

PRINCE EDWARD ISLAND
DISABILITY SUPPORT PROGRAM:
TELEPHONE SURVEY

Final Report

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Prepared for:
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Charlottetown, Prince Edward Island

**Baker
Consulting
Inc**

Charlottetown • Prince Edward Island



Prince Edward Island Disability Support Program:
Telephone Survey

Table of Contents

1. Introduction	1
1. Purpose and Methodology	1
2. Implementation and Outcomes	2
2.1 Survey No. 1: Active Files	3
2.1.1 Conditions of Living	7
2.1.2 Needs	10
2.1.3 Employability	14
2.1.3.1 Paid Employment	14
2.1.3.2 Volunteer Work	15
2.1.4 DSP Staff Service Quality	16
2.1.5 Satisfaction with the Disability Support Program	17
2.2 Survey No. 2: Former Program Participants	19
2.3 Survey No. 3: Ineligible Applicants	20
2.4 Survey No. 4: Other DSP Contacts	21

Appendices: Survey participant comments



1. Introduction

1. Purpose and Methodology

Responding to an open competitive call for proposals (PEIGOV RFP#224), Baker Consulting Inc. was awarded a contract by the Province of Prince Edward Island's Department of Health and Social Services (DHSS) to conduct a quantitative telephone survey among participants in the province's Disability Support Program (DSP). The survey was in support of a formative evaluation of the program that was being conducted.

The purpose of the survey was to inform the Disability Support Program Evaluation Management Team on a wide range of issues and questions. Key queries of the survey were to include:

- participant satisfaction with the program;
- participant independence;
- participant quality of life; and
- changes to employment/employability and income.

The survey was to be administered with the following objectives in mind:

1. satisfy provincial reporting requirements;
2. document and evaluate program changes;
3. provide participant profile and program information;
4. provide baseline and participant satisfaction data; and
5. evaluate program delivery including unintended impacts and effects, gaps in service and value-for-money.

The methodology identified for this project was a quantitative survey with data collection being done via a telephone interview, using a standardized questionnaire. Data collection was conducted from one central location using computer-aided telephone interviewing (CATI) technology. The sample list was an electronic database of current and former participants in the Disability Support Program which was provided by the client.

Technical details of the research can be found in a pre-survey document prepared for this assignment, *Prince Edward Island Disability Support Program: Participant Survey Methodology Plan*.

2. Implementation and Outcomes

The scope of the telephone research was expanded beyond the original target population of current and former participants in the Disability Support Program to include:

- individuals who had applied for DSP supports but had been deemed ineligible; and
- individuals where an electronic administrative database record of contact but no application existed, or where an application had been approved but supports had never been accessed.

In the end, four survey instruments were utilized:

1. No. 1: Current program participants;
2. No. 2: Former program participants where the administrative coding for closing the file was TD: Service objectives met;
3. No. 3: Program applicants deemed ineligible with an administrative coding of TG: Income or assets exceed qualifying level, TL: Failure to meet eligibility criteria or TS: Client contribution exceeds level of need; and
4. No. 4: Successful applicants or partial applicants with administrative codes of TB: Client refuses service, TI: Information not fully supplied, TK: Inappropriate referral or TP: Alternate arrangements made.

Call activity outcomes are summarized below:

	Disability Support Program Telephone Survey			
	Survey Instrument			
	No. 1 Active	No. 2 Closed	No. 3 Ineligible	No. 4 Other
Date opened	13JUN03	20JUN03	20JUN03	11JUL03
Date closed	15JUL03	15JUL03	15JUL03	23JUL03
Gross names	913	205	49	56
Net names	896	199	48	56
Wrong number	34	5	5	2
Not in service	35	7	4	1
Fax tone	5	1		
Self disqualified	29	23	7	7
Refusal	66	19	8	2
Non completed interrupts	25	2		
Completes	508	94	15	36
Eligibility not established	194	48	9	8
	896	199	48	56
Response rate	65.5%	63.4%	53.0%	82.4%

Exhibit 1

2.1 Survey No. 1: Active Files

At the time the survey was initiated, there were 913 active files on record. Thirteen records had no telephone number and no attempt was made to correct this, while four records appeared to be duplicates. Consequently, the survey dataset contained 896 records. A total of 508 surveys were completed representing a completion rate of 65.1%.

For this report, the word "client" is used to describe the DSP participant associated with an interview in order to avoid confusion with actual survey "participants," who could be a client or a client proxy. The initial contact person for the survey could be either the client or a potential proxy. Clients in the dataset less than the age of 18 years were automatically flagged for a proxy contact defined as the "head of household" individual in the case file. For clients 18 years of age and older, each disability support worker reviewed his or her case files and indicated the files where from their knowledge they felt the client would be able to participate in a telephone survey in a meaningful way. In cases where it was felt that the client could not, the worker was asked to provide the name of a potential proxy.

The initial split of client to proxy in the survey dataset was 00% client and 00% proxy. The survey instruments utilized allowed interviewers to switch from client to proxy depending on the situation. Among completed surveys the client to proxy mix was 21% client and 79% proxy. Among the proxies, 70% were a parent.

Survey completed by...

	Frequency	Percent
Participant	106	20.9
Proxy	402	79.1
Total	508	100.0

Exhibit 2

Proxy Relationship to Participant

	Frequency	Percent
Parent	282	70.1
Other relative	41	10.2
Friend	10	2.5
Paid caregiver	49	12.2
Trustee	11	2.7
Other	9	2.2
Total	402	100.0

Exhibit 3

The distribution of survey clients across the province followed general client patterns with the highest response coming from Queens (43%), followed by East Prince (23%), West Prince (17%), and Kings (18%).

Health Region

	Frequency	Percent
West Prince	84	16.5
East Prince	115	22.6
Queens	219	43.1
Kings	90	17.7
Total	508	100.0

Exhibit 4

The age of the client was generally older with 59% being aged 30 years or older. Sixty-three percent (63%) of clients had a developmental/intellectual disability while another 11% had both physical and development/intellectual disabilities.

Prince Edward Island Disability Support Program:
Telephone Survey

Disability		
	Frequency	Percent
Physical	130	25.6
Developmental/Intellectual	320	63.0
Physical and Developmental/Intellectual	56	11.0
Mental illness	2	.4
Total	508	100.0

Exhibit 6

An examination of the mix of client/proxy surveys by disability shows that 67% of clients who completed the survey had a physical disability while 73% of the clients represented by proxies had a developmental/intellectual disability

Age of DSP Participant		
	Frequency	Percent
0 to 5	19	3.7
6 to 12	64	12.6
13 to 17	34	6.7
18 to 29	92	18.1
30 to 39	79	15.6
40 to 49	118	23.2
50 to 59	68	13.4
60+	34	6.7
Total	508	100.0

Exhibit 5

Survey Completion by Participant/Proxy and Participant Disability (%)

		Survey completed by...		
		Participant	Proxy	Total
Disability	Physical	67.0	14.7	25.6
	Developmental/Intellectual	26.4	72.6	63.0
	Physical and Developmental/Intellectual	5.7	12.4	11.0
	Mental illness	.9	.2	.4
Total		100.0	100.0	100.0

Exhibit 7

Clients represented in the survey clients were generally higher functioning with two-thirds being either medium or high functioning. When response is examined by respondent, two-thirds of the clients were high functioning while 90% were either high or medium functioning. Sixty percent (60%) of clients represented by proxies are identified as being either high or medium functioning (31% high and 29% medium) while 24% are identified as being low functioning and 13% very low.

Overall Functioning		
	Frequency	Percent
High	196	38.6
Medium	140	27.6
Low	107	21.1
Very low	53	10.4
Unknown	12	2.4
Total	508	100.0

Exhibit 8

Survey Completion By Participant/Proxy and Participant Overall Functioning (%)

		Survey completed by...		
		Participant	Proxy	Total
Overall functioning	High	66.0	31.3	38.6
	Medium	23.6	28.6	27.6
	Low	8.5	24.4	21.1
	Very low		13.2	10.4
	Unknown	1.9	2.5	2.4
Total		100.0	100.0	100.0

Exhibit 9

Matching administrative data to completed surveys, close to 69% of adult clients represented are presently receiving income support from the provincial government. Based on response from survey participants, 59% of DSP clients live with a parent, followed, cumulatively, by 18% who live in their own home, either with independently, with a spouse or partner, or with roommates.

Adults Receiving Income Support

	Frequency	Percent
Yes	282	69.1
No	126	30.9
Total	408	100.0

Exhibit 10

Place of residence

	Frequency	Percent
Own home independently	41	8.1
Own home with husband, wife, partner	36	7.1
Own home with roommates	8	1.6
With mother or father	299	58.9
With another relative	30	5.9
Group home	19	3.7
Boarding home	24	4.7
Other	50	9.8
Don't know/No response	1	.2
Total	508	100.0

Exhibit 11

Survey participants were asked about their understanding of the DSP and program information that they had received. As can be seen in Exhibit 12, 72% of respondents said that they knew "what the Disability Support Program is." The lowest awareness was among client participants where 58% indicated that they didn't know or weren't sure what the DSP was.

Survey completed by...	Awareness of Disability Support Program (%)				Total
	Yes	No/Not really	Response unclear	Don't know/No response	
Participant	42.5	57.5			100.0
Proxy	79.9	19.4	.5	.2	100.0
Total	72.0	27.4	.4	.2	100.0

Exhibit 12

Among respondents who said they knew what the DSP was, 56% reported that they had received DSP pamphlets or brochures, while 44% reported that they hadn't or didn't know (Exhibit 13).

Has received DSP pamphlets or brochures

	Frequency	Percent
Yes	203	55.5
No	126	34.4
Don't know/No Response	37	10.1
Total	366	100.0

All survey participants were asked if they understood what supports and services were

Exhibit 13 Among survey respondents who reported they knew what the Disability Support Program was

Prince Edward Island Disability Support Program:
Telephone Survey

Survey completed by	Understands DSP supports and services (%)				Total
	Yes	No/Not really	Response unclear	Don't know/No response	
Participant	47.2	52.8			100.0
Proxy	65.4	32.6	1.2	.7	100.0
Total	61.6	36.8	1.0	.6	100.0

Exhibit 14

available under the Disability Support Program. Sixty-two percent (62%) reported that they did while 37% either didn't or weren't sure (Exhibit 14). A much higher percentage of proxies said that they understood what supports and services were available under the DSP than did client participants. When examined by health region, there was consistency in reported understanding among three of the health regions while East Prince scored noticeably lower (Exhibit 15). This is not explainable by client/proxy participation levels as Exhibit 16 shows that East Prince had the second highest participation level by proxies among the health regions.

Health Region	Understanding of DSP supports and services (%)				Total
	Yes	No/Not really	Response unclear	Don't know/No response	
West Prince	61.9	36.9		1.2	100.0
East Prince	53.9	44.3	.9	.9	100.0
Queens	64.8	33.3	1.4	.5	100.0
Kings	63.3	35.6	1.1		100.0
Total	61.6	36.8	1.0	.6	100.0

Exhibit 15

Survey completed by...	Health Region				Total
	West Prince	East Prince	Queens	Kings	
Participant	14.0	9.5	15.3	4.2	12.3
Proxy	86.0	90.5	84.7	95.8	87.7
Total	100.0	100.0	100.0	100.0	100.0

Exhibit 16

The survey content itself consisted of a series of questions that were built around seven dimensions:

1. quality of life;
2. barriers;
3. independence;
4. needs;
5. employability;
6. DSP staff service quality; and
7. satisfaction with the Disability Support Program.

The balance of this section deals with survey responses grouped by dimension.

2.1.1 Conditions of Living

Questioning in three dimensions, quality of life, barriers and independence, were designed to provide insight into conditions of living for DSP clients.

Quality of Life

The first conditions of living dimension was quality of life. The wording of each question alternated depending upon whether the survey participant was a client or proxy. For example, a client question would be "Do you like living where you are?" while the proxy question would be "Does <client's first name> like living where <he/she> is living?" To exhibit sensitivity, not all questions were asked of all survey participants. For example, proxies of clients aged less than 17 years were not asked questions about the client's home and neighbourhood safety; proxies of clients aged less than seven were not asked questions that were inappropriate to that age group; and parent-proxies of clients living with a parent were not asked questions such as whether or not the client would like to be living somewhere else.

Responses to questions were yes/no, happy/unhappy on no scale. Exhibit 17 below summarizes the quality of life questions by percent response based on the total number of survey participants who were asked each question. Percentages for negative questions have been reversed to accurately reflect the negative/positive sense of the question. Response has also been reported by both client and proxy.

Dimension: Quality of Life	Positive		Negative		No Response	
	Client	Proxy	Client	Proxy	Client	Proxy
	%	%	%	%	%	%
1 Do you like living where you are?	91.5	98.3	7.5	0.8	0.9	0.8
2 Do you feel safe inside where you are living?	97.2	99.6	1.9	0.4	0.9	0.0
3 Do you feel safe outside in your neighbourhood?	93.4	88.6	5.7	8.9	0.9	2.5
4 Would you like to live somewhere else?	80.2	85.2	18.9	11.9	0.9	2.9
5 Do you have friends you like to talk to or do things with?	91.5	81.1	8.5	18.4	0.0	0.5
6 Do you often feel like you do not have anyone to talk to?	68.9	70.5	27.4	26.5	3.8	3.1
7 Do you have any best friends, someone you can talk to about private things?	84.0	59.7	14.2	38.0	1.9	2.3
8 On most days, are you usually happy?	85.8	94.3	8.5	4.0	4.7	1.7
9 On most days, are you usually sad?	83.3	0.0	9.3	0.0	7.4	0.0
10 Are you happy most of the time with how you spend your fun or free time?	81.8	80.2	10.9	6.3	7.3	13.5
11 Are you unhappy most of the time with how you spend your fun or free time?	72.2	0.0	16.7	0.0	11.1	0.0
12 Do you have enough things to do around home during your free time?	83.0	62.2	15.1	31.3	1.9	6.5
13 Are you happy with the amount of time you spend with your family?	85.2	86.6	13.1	8.2	1.6	5.2
14 Are you unhappy with the amount of time you spend with your friends?	78.7	0.0	19.1	0.0	2.1	0.0
15 Are caregivers and staff who help you nice to you? Are they polite to you?	93.3	0.0	2.2	0.0	4.4	0.0
In the past month...						
16 Gone out to visit family or friends	84.0	84.3	15.1	14.9	0.9	0.7
17 Gone grocery shopping	80.2	72.1	19.8	27.4	0.0	0.5
18 Gone shopping for things other than groceries	58.5	76.1	41.5	23.4	0.0	0.5
19 Done any physical activity such as exercise, walk or play sports	65.0	80.3	30.2	18.7	3.8	1.0
20 Gone to a party, dance, movie or restaurant with friends, family or a partner	65.1	69.5	34.9	30.1	0.0	0.3
21 Gone outside your home for a hobby or favourite activity	55.7	60.4	43.4	33.1	0.9	6.5
22 Gone to any event at a church or other place of worship	59.4	42.5	40.6	57.0	0.0	0.5
23 Gone for a walk outside with family or friends	48.1	82.8	51.9	16.9	0.0	0.2
24 Gone to a sporting event, a music concert, a play or a movie	34.9	50.7	65.1	44.0	0.0	5.2
	1823	1525	521	420	56	55
	76.0	76.3	21.7	21.0	2.3	2.7
	76.1		21.4			

Exhibit 17

To arrive at an overall measure of quality of life, individual percent responses were aggregated by category and an overall percent calculated based on the total aggregate score. The client/proxy scores were then aggregated into a total score for positive and negative.

Among the individual questions there are some cases of significant differences in responses between clients and proxies. In these situations, additional research may be warranted to better understand and potentially respond to needs that may be driving the differences. Overall, however, the total quality of life scores between clients and proxies were very similar with 76% of client responses scoring positive and 76.3% of proxy responses scoring positive.

Barriers

Barriers is the second dimension investigated with respect to conditions of living, addressing the impact to people with disabilities of barriers. As with the quality of life dimension, the wording of questions was structured differently for clients and proxies and not all questions applied to all client demographics. Results of the barriers dimension questions are summarized below in Exhibit 18.

Dimension: Barriers	Positive		Negative		No Response	
	Client	Proxy	Client	Proxy	Client	Proxy
	%	%	%	%	%	%
1 Can you move around in your home as much as you need to?	85.8	90.8	13.2	9.0	0.9	0.2
2 Is moving around your home easy or very easy?						
3 Is moving around your home difficult or very difficult?						
4 Is it easy for you to enter and leave your home?	81.1	83.1	17.9	15.9	0.9	1.0
5 Is it easy or very easy?						
6 Is it difficult or very difficult?						
7 Do you have someone to help you when you need help?	85.1		13.4		1.5	
8 Can you move around outside your home as much as you need to?	73.3	78.4	24.8	19.9	1.9	1.7
9 Is it easy or very easy?						
10 Is it difficult or very difficult?						
11 Changes in past year have made it easier to do outside activities	30.2	25.6	67.9	72.6	1.9	1.7
12 Can get from home to outside activities as much as wants/needs to	75.5	80.1	22.6	16.9	1.9	3.0
13 Is it difficult or very difficult?						
14 Are there barriers that make it hard for you to get to work?	42.9	19.0	55.1	76.7	2.0	4.3
15 Are these barriers difficult or very difficult?						
16 Aids or equipment are needed that client does not have	67.0	13.0	33.0	85.5	0.0	1.5
17 Client needs "someone's help" that they do not have	64.2	52.0	34.9	45.5	0.9	2.5
18 Client does not have a way of getting to places	49.1	63.4	50.9	35.3	0.0	1.2
19 There are no places or programs close to where client lives	55.7	54.0	34.9	40.3	9.4	5.7
20 There is insufficient life skills or job skills coaching available		47.3		37.8		14.9
21 Cost of disability supports or services needed is too expensive	41.5	42.5	50.0	47.8	8.5	9.7
	75.1	64.9	41.9	50.3	3.0	4.8
	62.6	54.1	34.9	41.9	2.5	4.0
	58.4		38.4			

Exhibit 18

The overall positive score of 58.4% for the barriers dimension is notably lower than the overall positive score of 76.1% for the quality of living dimension. It is also notable that proxies have a less positive outlook towards barriers (54.1%) than clients (62.6%). This difference may partly be explained by the fact that 38% of the clients represented by proxies were classified with an overall

level functioning of low or very low, while only 10% of the client participants were in either of these two categories.

Unlike the quality of life questions, some barriers questions used an expanded scale of easy/very easy or difficult/very difficult to gauge degree of ease or difficulty. Exhibit 19 below summarizes survey participant responses by client and proxy for these degree of difficulty questions.

	Very Easy		Easy		Difficult		Very Difficult		No Response	
	Client	Proxy	Client	Proxy	Client	Proxy	Client	Proxy	Client	Proxy
	%	%	%	%	%	%	%	%	%	%
1 Moving around home is easy/very easy/difficult/very difficult	29.5	44.4	52.7	45.7	8.0	3.2	4.5	6.2	5.4	0.5
2 Entering and leaving home is easy/very easy/difficult/very difficult	33.9	47.1	42.0	35.7	12.5	6.2	3.6	9.7	5.4	0.5
3 Moving around outside home is easy/very easy/difficult/very difficult	19.6	40.0	47.3	37.5	10.7	6.5	12.5	13.2	2.7	2.0
4 Getting from home to outside activities is difficult/very difficult					5.4	7.9	14.3	8.7	1.6	0.5
5 Barriers to getting to work are difficult/very difficult					6.3	13.4	11.6	38.5	1.8	1.2

Exhibit 19

Independence

The third dimension used to explore conditions of living was independence. As with the previous two dimensions, question structured switched between client and proxy participants and not all questions were asked depending upon factors such as client age. Exhibit 20 below summarizes the results of the independent dimension questions.

Dimension: Independence	Positive		Negative		No Response	
	Client	Proxy	Client	Proxy	Client	Proxy
	%	%	%	%	%	%
1 Do you need someone to help you in your home?	39.6		60.4		0.0	
2 Client requires paid day programming or one-to-one support		28.6		67.9		3.5
3 Did you choose the place you live yourself?	80.7	61.3	18.2	38.7	1.1	0.0
4 Did you help decide who lives with you?	75.0	34.9	25.0	62.8	0.0	2.3
5 Where you live, can you usually be alone by yourself when you want to?	92.5	80.1	6.6	18.8	0.9	1.0
6 Can you decide when to eat, do house chores or go out?	92.5	50.3	5.7	47.9	1.9	1.7
7 Do you usually choose the things you do for fun?	96.2	83.6	1.9	15.1	1.9	1.4
8 Can you usually go shopping when you want to?	67.0	56.2	28.3	39.0	4.7	4.8
9 Can you usually go out for exercise or sport when you want to?	62.3	67.8	29.2	27.7	8.5	4.5
10 Can you usually go out for fun when you want to?	75.5	66.4	21.7	29.8	2.8	3.8
11 Are you often worried about not having enough money for the things you need?	75.5	36.6	22.6	60.9	1.9	2.5
12 When you get mail, do you usually open it yourself?	92.5	55.1	7.5	18.5	0.0	0.5
13 When others open your mail, do they usually ask you first?	87.4	72.1	5.3	7.9	7.4	20.0
14 At home, can you use the telephone when you want to?	99.1	62.3	0.9	31.8	0.0	5.8
15 Can you usually see your friends when you want to see them?	86.8	80.5	12.3	11.6	0.9	7.9
16 Client requires regular supervision either at home or away from home	80.0	21.1	20.0	78.6	0.0	0.3
17 Can you have your own money whenever you want it?	90.6	58.9	8.5	35.6	0.9	5.5
18 Do you usually choose the things you want to buy?	95.3	81.8	2.8	14.7	1.9	3.4
	1368	998	277	608	35	69
	81.7	59.6	16.3	36.3	2.1	4.1
	70.7		26.2			

Exhibit 20

At 70.7%, the overall positive score is high which, based on the questions asked, is a reflection of a high perception of independence among survey participants. Once again the difference in positive

scores between clients and proxies is notable and could possibly be once again a reflection of the higher level of overall functioning among client survey participants.

Exhibit 21 below illustrates the three dimensions as a reflection of conditions of living for DSP clients. As previously noted, quality of life scores highest followed by independence. Barriers exhibits the strongest negative impact on conditions of living.

DSP Telephone Survey

Key Conditions of Living Measures

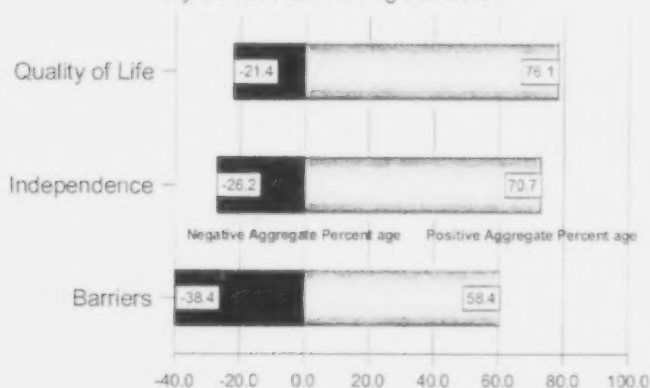


Exhibit 21

2.1.2 Needs

A series of closed- and open-ended questions in the telephone survey explored perceived needs of both clients and proxies.

Exhibits 22 to 27 summarize six questions that were asked of proxies of clients 12 years of age or younger to gain insight into counselling and other direct supports that be needed. Exhibits 22, 23 and 24 were counselling/information related. Among these three questions, a perceived need of medium or high ranged from 56% to 75%, suggesting that a strong need exists for these types of supports.

Survey completed by	Need for family or individual counselling and social support to cope with client's disability (%)			
	Low	Medium	High	Total
Proxy	40.7	30.2	29.1	100.0
Total	40.7	30.2	29.1	100.0

Exhibit 22

Survey completed by...	Parent/caregiver need for information about disability, his/her behaviour, or services that are available for children (%)			
	Low	Medium	High	Total
Proxy	24.4	30.2	45.3	100.0
Total	24.4	30.2	45.3	100.0

Exhibit 23

Survey completed by...	Family or individual counselling and social support to explain disability to others (%)				
	Low	Medium	High	Don't know/No response	Total
Proxy	38.2	29.2	27.0	5.6	100.0
Total	38.2	29.2	27.0	5.6	100.0

Exhibit 24

The last three questions (Exhibits 25, 26, 27) dealt with respondents' perceived need for child care, respite and financial support for special needs. As can be seen, 75% of respondents ranked their perceived need for additional child care as medium or high, while the perceived need for more respite was ranked medium or high by 78% of respondents, and the perceived need for more financial support for special needs was ranked as medium or high by 88% of respondents.

Survey completed by...	Child care (%)				
	Low	Medium	High	Don't know/No response	Total
Proxy	23.6	20.2	55.1	1.1	100.0
Total	23.6	20.2	55.1	1.1	100.0

Exhibit 25

Survey completed by...	Respite care (%)				
	Low	Medium	High	Don't know/No response	Total
Proxy	21.3	22.5	55.1	1.1	100.0
Total	21.3	22.5	55.1	1.1	100.0

Exhibit 26

Survey completed by...	Financial support for individual's special needs (%)				
	Low	Medium	High	Don't know/No response	Total
Proxy	11.2	18.0	69.7	1.1	100.0
Total	11.2	18.0	69.7	1.1	100.0

Exhibit 27

Survey participants were asked if there were important disability support goods or services that were needed and either the client or proxy did not have. As can be seen in Exhibit 28, there was a relatively even split between responses which is notable in that almost half the survey respondents have the perception that there is an important need that is unmet.

Survey completed by...	Are there important disability support goods or services that participant/proxy needs and does not have (%)				Total
	Yes	No	Response unclear	Don't know/No response	
Participant	45.3	50.9		3.8	100.0
Proxy	44.5	47.8	2.0	5.7	100.0
Total	44.7	48.4	1.6	5.3	100.0

Exhibit 28

In line with the question above, all survey participants were asked to name one new support or more of a support that was currently being received that would make their lives better. Responses are published in Appendix A by client and proxy. Not surprisingly, the responses are diverse, but an analysis shows four main themes emerging:

1. income support in general;
2. transportation;
3. respite; and
4. social and recreational activities.

All survey respondents were also asked to name one barrier where reducing/eliminating that would make the client's life better. Responses by client and proxy are published in Appendix B and reflect the breadth of physical, architectural, attitudinal, communication and policy barriers that people with disabilities encounter on a day-to-day basis. The responses also reflect a need for a flexible and individualized approach to disability support planning which supports the Disability Support Program model. The breadth and nature of response makes cluster analysis and the identification of key themes difficult within the scope of the research budget, and additional analysis may provide useful insights.

Lastly, survey participants were asked a series of questions about what might be preventing the client from doing more fun, social or work activities. Responses to these questions are summarized in Exhibits 29 to 34 beginning on the next page. Notable feedback includes the following:

- one-third of clients reported that they needed specialized aids or equipment that they did not have;
- 43% of respondents reported that the client needed someone's help that he or she did not have;
- 51% of clients and 35% of proxies reported that transportation services were needed that the client did not have;

Survey completed by...	Participant needs specialized aids or equipment that he/she does not have (%)				Total
	Yes	No	Response unclear	Don't know/No response	
Participant	33.0	67.0			100.0
Proxy	12.9	84.8	.2	2.0	100.0
Total	17.1	81.1	.2	1.6	100.0

Exhibit 29

Survey completed by...	Participant needs someone's help that he/she does not have (%)				Total
	Yes	No	Response unclear	Don't know/No response	
Participant	34.9	64.2	.9		100.0
Proxy	45.5	52.0	.2	2.2	100.0
Total	43.3	54.5	.4	1.8	100.0

Exhibit 30

Survey completed by...	Participant needs transportation services that he/she does not have (%)				Total
	Yes	No	Response unclear	Don't know/No response	
Participant	50.9	49.1			100.0
Proxy	35.3	63.4	.5	.7	100.0
Total	38.6	60.4	.4	.6	100.0

Exhibit 31

Survey completed by...	No facilities or programs are available locally for participant needs that he/she does not have (%)				Total
	Yes	No	Response unclear	Don't know/No response	
Participant	34.9	55.7	2.8	6.6	100.0
Proxy	40.3	54.0	1.2	4.5	100.0
Total	39.2	54.3	1.6	4.9	100.0

Exhibit 32

Survey completed by...	Cost of needed disability supports and services is too expensive (%)				Total
	Yes	No	Response unclear	Don't know/No response	
Participant	50.0	41.5	3.8	4.7	100.0
Proxy	47.8	42.5	.5	9.2	100.0
Total	48.2	42.3	1.2	8.3	100.0

Exhibit 33

Prince Edward Island Disability Support Program:
Telephone Survey

Survey completed by...	There are insufficient life skills or job skills coaching available (%)				
	Yes	No	Response unclear	Don't know/No response	Total
Proxy	37.8	47.3	1.5	13.4	100.0
Total	37.8	47.3	1.5	13.4	100.0

Exhibit 34

- 40% of all respondents reported that there was a lack of adequate facilities or programs;
- 48% of all respondents reported that the cost of needed disability supports was too expensive; and
- 38% of proxies reported that there was insufficient life skills or job skills coaching available.

2.1.3 Employability

2.1.3.1 Paid Employment

Clients or proxies of clients aged 18 years and older were asked a series of employment-related questions. Thirty-four percent (34%) of respondents reported that the client had had a paid job in the past year (Exhibit 36). Among the respondents who answered yes, 70% of clients were reported to currently have regular paid employment (Exhibit 37). This client cohort who were reported to currently have regular paid employment represents 24% of the entire survey sample.

Survey completed by...	Participant has had paid job in past year (Age 18-64) (%)				
	Yes	No	Response unclear	Don't know/No response	Total
Participant	22.6	76.4		.9	100.0
Proxy	38.0	61.3	.7		100.0
Total	33.8	65.5	.5	.3	100.0

Exhibit 35

Survey completed by...	Participant currently has regular paid employment (%)			
	Yes	No	Don't know/No response	Total
Participant	75.0	25.0		100.0
Proxy	69.2	29.9	.9	100.0
Total	70.2	29.0	.8	100.0

Exhibit 36

When examined by health region, 41% of those reporting to have regular paid employment were located in Queens, with 29% being located in East Prince, 19% in Kings and 11% in West Prince (Exhibit 37).

Participant currently has regular paid employment	% of N in Health Region				
	Health Region				
	West Prince	East Prince	Queens	Kings	Total
Yes	10.9	29.3	41.3	18.5	100.0
No	2.6	28.9	52.6	15.8	100.0
Don't know/No response		100.0			100.0
Total	8.4	29.8	44.3	17.6	100.0

Exhibit 37

The reported length of time that these clients had held regular paid employment ranged between one month and 26 years with a mean period of regular paid employment of 5.2 years. The mean number of hours worked "last week" was 15. Sixty-seven percent (67%) of respondents reported that the hours worked "last week" were "about the same" as the number of hours the client usually worked for pay a year ago. Another 21% reported that the number of hours worked "last week" was more than the numbers of hours the client usually worked for pay a year ago.

On a positive note, among those who had some type of paid employment in the past year, it was reported that:

- 23% started paid employment because of supports received through the DSP;
- 16% started better paying employment because of supports received through the DSP; and
- 18% started new paid employment that was more "fun" because of supports received through the DSP.

Among survey participants where the client did not have regular paid employment, 2% reported that the client would be starting a paid employment position "in the next month." Among those who would not be, 83% reported that the client's disability prevented him or her from doing any paid work, and 32% reported that there were barriers other than the client's disability that prevented him or her from doing any paid work.

2.1.3.2 Volunteer Work

Unpaid volunteer work is looked upon as an activity that can be as equally rewarding as paid employment. Among all survey respondents, 10% reported doing volunteer work "once a week or more" with a notable difference in response between clients and proxies (Exhibit 38). The mean length of time that this cohort had been volunteering was 4¼ years, while the mean number of hours volunteered "last week" was 5.6.

Survey completed by..	Does participant go anywhere to do volunteer work once a week or more (%)				Total
	Yes	No	Response unclear	Don't know/No response	
Participant	16.0	82.1	1.9		100.0
Proxy	8.2	91.5		.2	100.0
Total	9.8	89.6	.4	.2	100.0

Exhibit 38

Among this cohort of clients who did volunteer work once a week or more, it was reported that:

- 26% started doing volunteer work in the past year because of training or other services or supports received through the DSP; and
- 20% started volunteer work that was "more fun" because of training or other services or supports received through the DSP.

2.1.4 DSP Staff Service Quality

More than 90% of survey participants reported that they knew who their disability support worker (DSW) was. In terms of DSP staff service quality, survey participants were generally very positive as the summary of staff- and service-related questions below in Exhibit 39 shows. The weakest responses were in helping the client feel better about being able to do things for himself/herself (yes = 58%) and helping clients/proxies decide what supports and services to use (yes = 66%).

Disability Support Program Telephone Survey			
Disability Support Worker Service Quality Questions			
	Yes %	No %	Other %
Does participant/proxy know who their DSW is	91.3	7.9	0.8
From among survey participants who responded YES:			
Can participant/proxy talk to DSW whenever he/she needs	86.4	4.5	9.1
Does DSW understand participant's disability	81.9	5.1	13.0
Does DSW understand participant's needs	80.7	6.9	12.4
Does DSW do the things they say they will	81.7	5.1	13.2
Has DSW helped participant/proxy decide what supports and services to use	66.1	20.1	13.8
Has DSW helped participant feel better about being able to do things for himself/herself	57.5	23.4	19.1
Is participant/proxy happy overall with quality of help received from his/her DSW	60.1	8.3	11.6
Has participant/proxy been unhappy in the past year about any DSP support	17.7	78.9	3.4
From among survey participants who responded YES:			
Did participant tell DSW or anyone else	85.6	10.0	4.4
Was participant/proxy happy about how the complaint was fixed	20.8	75.3	3.9

Exhibit 39

Eighteen percent (18%) of clients/proxies reported that they had been unhappy with some aspect of the DSP in the past year. It is notable that among this cohort, 75% reported that they were unhappy with how the complaint was fixed.

2.1.5 Satisfaction with the Disability Support Program

More than half the survey participants (56%) reported that the client's life was better due to the supports received from the Disability Support Program in the past year (Exhibit 40). The positive impact appears to be highest among client participants where 69% reported that their life was better due to DSP supports received in the past year.

% with or better of DSP supports in past year (%)

Survey completed by...	Impact of DSP supports in past year. (%)					Total
	Better	Worse	About the same	Response unclear	Don't know/No response	
Participant	68.9	1.9	25.5	1.9	1.9	100.0
Proxy	52.5	2.2	42.3	1.5	1.5	100.0
Total	55.9	2.2	38.8	1.6	1.6	100.0

Exhibit 40

The importance of the Disability Support Program is reflected in the fact that 61% of survey participants reported that it would be difficult for the client to stay where he or she was presently living without the supports that were being received from the DSP (Exhibit 41).

Difficult for individual to stay where living without DSP supports (%)

Survey completed by...	Difficult for individual to stay where living without DSP supports (%)				Total
	Yes	No	Response unclear	Don't know/No response	
Participant	74.5	20.8	.9	3.8	100.0
Proxy	57.2	29.1	2.0	11.7	100.0
Total	60.8	27.4	1.8	10.0	100.0

Exhibit 41

Overall, 64% of survey participants reported that the services that were important to the client/proxy were covered under the DSP, while 58% reported the level of financial assistance available under the DSP as acceptable. Twenty-seven percent (27%) reported that changes in the past year have made it easier for the client do things like go to work, go shopping or attend social/recreational activities. Among this 27%, almost three-quarters attributed the changes to financial support received through the DSP.

Lastly, overall satisfaction with the supports and services received is summarized on the next page by age of client; overall level of functioning; and health region. With respect to client age, the 50 to 59 years age group was the most satisfied while the 0 to 5 years age group was the least satisfied. There is a distinct division in satisfaction between 0 to 29 years and 30 to 60+ years and a test of difference confirms a statistically significant difference between the two clusters.

With respect to overall level of functioning, program satisfaction declines as overall level of functioning declines, and a test of difference shows a statistically significant difference between high/medium and low/very low clusters.

Prince Edward Island Disability Support Program:
Telephone Survey

Lastly, using a scoring method of very happy = 4, happy = 3, unhappy = 2 and very unhappy = 1, program satisfaction was highest in West Prince with an aggregate score of 302, followed by Queens at 288, Kings at 285 and East Prince at 271.

Age of Participant	Overall participant/proxy satisfaction with supports and services received under the DSP (%)						
	Very happy	Happy	Unhappy	Very unhappy	Response unclear	Don't know/No response	Total
0 to 5	26.3	36.8	5.3	31.6			100.0
6 to 12	23.4	51.6	7.8	14.1		3.1	100.0
13 to 17	17.6	44.1	14.7	17.6		5.9	100.0
18 to 29	22.8	51.1	7.6	15.2		3.3	100.0
30 to 39	32.9	48.1	2.5	11.4	2.5	2.5	100.0
40 to 49	26.3	54.2	9.3	5.9	.8	3.4	100.0
50 to 59	27.9	57.4	11.8	1.5	1.5		100.0
60+	20.6	61.8	11.8	5.9			100.0
Total	25.6	52.0	8.5	10.6	.8	2.6	100.0

Exhibit 42

Overall functioning	Overall participant/proxy satisfaction with supports and services received under the DSP (%)						
	Very happy	Happy	Unhappy	Very unhappy	Response unclear	Don't know/No response	Total
High	29.1	52.6	7.1	9.2		2.0	100.0
Medium	23.6	57.1	8.6	6.4	2.1	2.1	100.0
Low	24.3	46.7	9.3	15.0	.9	3.7	100.0
Very low	20.8	49.1	9.4	20.8			100.0
Unknown	25.0	41.7	16.7			16.7	100.0
Total	25.6	52.0	8.5	10.6	.8	2.6	100.0

Exhibit 43

Health Region	Overall participant/proxy satisfaction with supports and services received under the DSP (%)						
	Very happy	Happy	Unhappy	Very unhappy	Response unclear	Don't know/No response	Total
West Prince	31.0	53.6	4.8	7.1		3.6	100.0
East Prince	19.1	51.3	14.8	11.3	.9	2.6	100.0
Queens	27.4	50.2	7.8	12.3	.9	1.4	100.0
Kings	24.4	55.6	5.6	8.9	1.1	4.4	100.0
Total	25.6	52.0	8.5	10.6	.8	2.6	100.0

Exhibit 44

A final question asked survey participants if there was anything about the Disability Support Program that they would like to comment on. Responses can be found in Appendix C.

2.2 Survey No. 2: Former Program Participants

As mentioned, the second survey involved former DSP participants coded "TD" or "service objectives met." From a survey dataset of 199 files, 99 surveys were completed representing a response rate of 63.4% (see Exhibit 1).

Exhibit 45 summarizes former participants by age grouping. As can be seen, 71% were aged 40+ years. This older population is reflected in the fact that the mean client age was 43.

Services received are summarized below in Exhibit 46. While multiple services may have been accessed, financial assistance and were dominated by financial assistance for an aid or device.

Client Age		
	Frequency	Percent
0 to 5	1	1.1
6 to 12	6	6.4
13 to 17	3	3.2
18 to 29	8	8.5
30 to 39	9	9.6
40 to 49	29	30.9
50 to 59	26	27.7
60+	12	12.8
Total	94	100.0

Exhibit 45

DSP Telephone Survey: Closed TD Files Services Received	
	%
Planning support to help cope with a disability	5.3
Planning support to organize community services	3.2
Financial assistance for a home/vehicle modification	7.4
Financial assistance for employment training/support	2.1
Financial assistance for a community social or leisure activity	4.3
Financial assistance for an aid or device	73.4
Other planning support/financial assistance	19.1
Total greater than 100% due to multiple response	114.8

Exhibit 46

Among the 83 clients who were aged 18+ years, 60% (n=50) reported that they had regular paid employment. Among this group, 68% (n=34) reported that the supports received through the DSP either helped obtain employment or improve an employment situation. Among clients aged 18+ years who reported that they did not have regular paid employment, 76% reported that their disability prevented them from doing any paid work.

Among all respondents, other reported client benefits derived as a result of DSP supports included:

- improved mobility (49%);
- improved physical activity (39%); and
- improved ability to enjoy leisure or social activities (79%).

Exhibit 47 on the next page illustrates that survey participants had very positive things to say about the disability support workers they dealt with. It is notable that 26% of the survey participants did not remember the worker they dealt with. Among those who did, 93% rated their overall level of

satisfaction with their disability support worker as "good" on a scale of poor, fair, good.

Disability Support Program Telephone Survey: Closed TD Files
Disability Support Worker Service Quality Questions

	Yes	No/Not Sure	Other
	%	%	%
Does survey participant/proxy remember the DSW he/she dealt with	70.8	27.1	2.1
From among survey participants who responded YES:			
Did DSW treat survey participant/proxy with respect	98.5	1.5	0.0
Did DSW understand client's disability	92.6	5.9	1.5
Did DSW understand client's needs	92.6	5.9	1.5
Did DSW do the things they say they would	92.5	6.0	1.5
Did DSW help participant/proxy decide what supports and services to use	73.1	25.4	1.5

Exhibit 47

Two summary questions were asked of survey participants with respect to the type and amount of services or supports received. On a scale of low, medium or high, 80% of survey participants rated their level of satisfaction with the TYPE of services or supports received as high. On the same scale, 80% percent rated their level of satisfaction with the AMOUNT of services or supports received as high.

2.3 Survey No. 3: Ineligible Applicants

In survey number three, attempts were made to contact 48 names on file of individuals who had applied to the DSP but had been deemed ineligible. A total of 13 surveys were completed representing a response rate of 53% (see Exhibit 1). Given the small size of the dataset, the number of invalid outcomes (i.e. wrong and out-of-service numbers and self-disqualified individuals) and the relatively small number of completes, the reliability of the survey results should be treated with caution.

Client ages ranged from 3 to 64 years with a mean age of 33 years. While 29% reported applying to the DSP for financial assistance for an aid or device, 71% reported applying for planning or financial assistance that was "other" than six major categories described, including:

1. planning support to help cope with a disability;
2. planning support to organize services in the community;
3. financial assistance for a home or vehicle modification;
4. financial assistance for employment training or employment support;
5. financial assistance for a community social or leisure activity; and
6. financial assistance for an aid or device.

When asked if they remembered the disability support worker (DSW) they dealt with, only 29% said yes. Consequently, there is little reliability in reporting the outcomes of interaction with

representatives of the Disability Support Program.

Survey participants were asked, on a scale of good, fair or poor, how they rated the application and assessment process they went through with the DSP. Responses were inconclusive in that 31% reported poor, 38% reported fair and 23% reported good. However, when asked about the length of time it took to process the application, 69% had the perception that it was "reasonable."

When asked if their reason for ineligibility was "clearly explained," 54% of respondents reported yes, while 23% reported no and 23% were unclear. When asked how strongly the survey participant agreed or disagreed with the ineligibility ruling, 69% reported that they disagreed somewhat on a scale of agreed, agreed somewhat, neither agreed nor disagreed, disagreed somewhat and strongly disagreed.

Forty-six percent (46%) of survey participants reported that a process for having their application reviewed was explained to them, while 31% reported no and 23% didn't know or had no response. Only one survey participant (7%) reported that they had their application reviewed by a review committee.

Again, it should be restated that the reliability of the findings from this component of the research should be treated with caution.

Appendix E reports on responses by survey participants to the question of whether there was anything about the DSP and its supports and services that the survey participant wanted to comment on.

2.4 Survey No. 4: Other DSP Contacts

The last survey, number four, targeted successful applicants or partial applicants with administrative codes of TB: Client refuses service, TI: Information not fully supplied, TK: Inappropriate referral or TP: Alternate arrangements made. As illustrated in Exhibit 1, from a dataset of 56 potential contacts, a response rate of 82% was achieved.

Survey participants were first asked to describe the "nature of the disability that made you contact the Disability Support Program." Responses were disparate and no clear pattern of disability could be determined.

Survey participants were next asked questions about their level of need and the disability support worker (DSW) they dealt with. With respect to level of need, respondents reported a median need of high on a scale of low, medium or high. On a scale of yes or no, the median ranking of the DSW was yes with respect to whether or not the inquirer was treated with respect. On the same scale, the median ranking was yes in terms of whether or not the DSW understood the nature of the disability. A median ranking of yes was also scored with respect to whether or not the DSW

understood what the inquirer's needs were. Lastly, respondents gave DSWs a median overall satisfaction rating of good on a scale of poor, fair or good.

Survey participants were asked to describe why the interviewee did not complete an application or access disability support services. Participant responses are reported below.

Waiting for income tax returns to be done so now will proceed with accessing supports.

DSP doesn't provide what I needed or something like that.

Decided not to get closed circuit TV.

DSP wouldn't allow, but only one phone call from me...no application, no doctor's report, nothing.

Wanted voice computer for a job situation. DSP would not provide...don't understand why.

I had a heart attack and this kind of went by the wayside.

I was told it was based on family income and my husband makes too much money based on what I was able to find out.

From what I understand they mostly work with younger children in schools and not mature people.

Waiting to get new doctor so I can get a physical so he can send DSP a report on my condition then I will reapply for DSP financial support.

My son was put on a waitlist for a program and we won't be provided with any services until the program starts.

I received two hearing aids.

Can't really remember...just wanted money.

Ineligible due to currently receiving workers' compensation.

My income was outside the range they calculate for assistance.

Don't really remember. I've talked to so many programs I can't keep them straight.

Means testing, but it's not the only issue. We refuse to institutionalize him, that's not the answer. Horrendous frustration in dealing with people who don't know what the hell they're doing!

Means test...did not qualify but the \$14,000 wheelchair we paid for by \$175 a month for just that. We got nothing!

Won't help because of income but we have mortgage and have to eat! Medicine is \$2,000 to \$3,000 a year plus trips to hospital and doctors.

Funding not available because we get money from Social Services and that's all we can get, no more.

Cancelled due to long hospital stay so didn't need home care worker then.

Training or upgrading not available under the DSP for highly functional adults.

Typing course to help me get a job. Going to call first of week about transportation.

I refused to sign on to a discriminatory policy. The government says it's an income issue. I say it's a discrimination issue.

Could not get job coaching because funding was not there and no one to do it is the big problem.

Based on family income it's very fair. Did complete application and 50% of my hearing aid the DSP paid for.

High functioning autistic child and was told services we required were not covered under the DSP and didn't provide income info.

Told by DSP our children did not qualify. Speech impediments were not considered disability so speech therapy was covered under the DSP.

The only thing we qualified for was replacement of her hearing aid, but it didn't need replacing. For everything else we didn't qualify in the means testing.

We were told our income was over the allowable amount.

I didn't even know there was an application. I have been working with a PEI disability employment counsellor.

They told me I didn't qualify.

I didn't qualify, I don't know why, no one explained it to me. I am not getting any other cheques. I came home and cried afterwards because I thought they were going to help me.

When they mentioned income screening I had promised my husband he would never be responsible for [] as he has three other children to support and [] is not his son. They would not take into account support he was paying for two of his daughters as it was not pursuant to a court order. They wanted to take his Hep-C money into account when I had a letter from Ottawa saying they shouldn't. I got completely fed up with the process.

I inquired but no paperwork was done. They told me there was nothing available for me.

Lastly, survey participants were asked if there was anything about the Disability Support Program that they would like to comment on. Responses are reported in Appendix F.

Appendix A:

CLIENTS

QUESTION: IF YOU COULD RECEIVE ONE NEW SUPPORT OR MORE OF A SUPPORT THAT IS CURRENTLY BEING RECEIVED THAT WOULD MAKE YOUR LIFE BETTER, WHAT WOULD IT BE?

CURRENTLY I AM RECEIVING HELP WITH MY CLEANING LADY. I CANNOT THINK OF ANYTHING.

MORE MONEY TO BUY FOOD AND PAY BILLS. I CAN BARELY AFFORD TO EAT.

IF I HAD SOME FRIENDS.

JUST LITTLE MORE MONEY. I DO NOT GET A LOT RIGHT NOW.

MORE MONEY TO GET OUT, WE ARE ON A FIXED INCOME, AND IT IS USED UP ON THE EXTRA BILLS DUE TO THE ILLNESS AND EXTRA COSTS ASSOCIATED WITH IT.

MORE SPENDING MONEY.

MORE FINANCIAL SUPPORT.

THEY SHOULD ADDRESS MY DISABILITY.

TRAVELLING EXPENSES, FOR APPOINTMENTS, ETC.

I HAVE APPLIED FOR FINANCIAL AID BUT I HAVE NOT YET RECEIVED IT. THE WORKER CAME AND HELPED ME WITH THE PAPERS BUT I HAVE NOT HEARD BACK YET.

BETTER TRANSPORTATION.

I WOULD LIKE MORE MONEY TO BE ABLE TO HAVE MORE ENTERTAINMENT TIME AND DO MORE ACTIVITIES BECAUSE I AM PRETTY LIMITED THAT WAY.

HELP WITH HOUSEKEEPING.

I AM ALL RIGHT FOR NOW, I CANNOT REALLY THINK OF ANYTHING, BUT THE FUTURE IS A CONCERN.

MORE PERSONAL CARE. FOR INSTANCE, IT COSTS ME \$13 AN HOUR FOR PERSONAL CARE AND THEY WILL ONLY ALLOW 3 SHOWERS A WEEK AND THEY ONLY SUBSIDIZE IT \$2 PER HOUR. THEY SAY IT SHOULD COST \$8 PER HOUR BUT IN REALITY IT COSTS \$13, SO INSTEAD OF CONTRIBUTING \$6 I AM CONTRIBUTING \$11. I CANNOT DO THINGS LIKE WASH WINDOWS, CLEAR SNOW, YARD WORK, MINOR REPAIRS. SENIORS QUALIFY FOR HELP, BUT I DO NOT. I AM NO MORE ABLE TO DO THESE THINGS THAN SENIORS.

MONEY FOR DENTAL.

AN EXERCISE BIKE.

MONEY - FOR DENTAL BILLS, RECREATION & OTHER THINGS.

A JOB, I WOULD LIKE TO GET MY A+ CERTIFICATION, I HAVE A COUPLE YEARS OF COLLEGE, TO CERTIFY IN THE COMPUTER INDUSTRY THAT I AM A TECHNICIAN.

VISUAL AIDS.

MORE MONEY, SOME OF MY OWN PERSONAL INSURANCE HAS STOPPED THIS PAST JUNE. I HAVE FAMILY THAT ARE TRYING TO GET SOME HELP THROUGH OUR MINISTER OF HEALTH THROUGH LETTERS OF SUPPORT TO RECEIVE INSURANCE MONIES AGAIN. I DID HAVE A MAJOR INSURANCE SETTLEMENT BECAUSE OF THE ACCIDENT, AND WE SUED THEIR INSURANCE COMPANY FOR MONEY, BECAUSE THEY SAY THAT I WILL NEVER WORK AGAIN, FINANCIAL HELP FOR DAY TO DAY LIVING WOULD BE A GREAT HELP.

I WILL BE STARTING VOLUNTEER WEEK AT THE QEH IN SEPTEMBER.

TRAVELLING EXPENSES.

MORE INCOME TO HELP PAY BILLS, WE CAN HARDLY MAKE ENDS MEET.

MORE MONEY, GETTING OUT MORE SOCIALLY.

MORE MONEY SO I COULD HAVE A SOCIAL LIFE.

TRANSPORTATION IS A PROBLEM, I HAVE TO RELY ON FRIENDS OR OTHER PEOPLE.

MONEY FOR CLOTHES, THINGS FOR MYSELF.

I REALLY NEED A CANE.

MONEY FOR TECHNICAL EQUIPMENT - SPEECH SOFTWARE FOR COMPUTER "TALKING DEVICE".

I WOULD LIKE TO HAVE A FOOTSTOOL.

NEED SOMEONE WHO COULD COME MORE OFTEN TO HELP WITH HOUSEWORK, OR SOMEONE WHO COULD HELP TAKE ME PLACES, LIKE APPOINTMENTS, OR ANYTHING ELSE WHERE I WANTED TO GO OR DO.

THEY WOULD HAVE TO MAKE IT SO THAT THE PLACES IN CHARLOTTETOWN ARE ACCESSIBLE TO PEOPLE IN A WHEELCHAIR.

MONEY FOR GLASSES RE: I AM VISUALLY IMPAIRED AND NEED SPECIAL LENSES. ALSO TRANSPORTATION/TAXI MONIES ARE LIMITED AND I LIVE IN THE COUNTRY AND THINGS ARE NOT AS ACCESSIBLE AS I WOULD LIKE THEM TO BE.

HOMEMAKER 2 HOURS PER WEEK, BUT NEED HER FOR MORE TIME THAN THAT. SOMEONE TO RUN ERRANDS FOR ME (GROCERIES) IN THE WINTER BECAUSE IT IS VERY DIFFICULT FOR ME TO NAVIGATE OR LIFT, ESPECIALLY IN THE WINTER MONTHS.

MORE INCOME SO I WOULD NOT WORRY ABOUT THE BILLS ALL THE TIME, RECREATIONAL TRAVEL IS LIMITED, FAMILY MEMBERS CLEAN MY PLACE.

TRANSPORTATION

CAREGIVER TO TAKE ME OUT FOR WALKS.

AN EXERCISE PROGRAM, I NEED ONE ON ONE SUPPORT FOR IT, MY FAMILY IS NOT ALWAYS AVAILABLE.

MONEY FOR SOCIAL THINGS AND MEDICINE.

I NEED TO BE ABLE TO GET AROUND AND THERE ONLY SEEMS TO BE A FEW TAXI DRIVERS THAT WILL TAKE ME. THEY DO NOT LIKE TAKING PEOPLE IN WHEELCHAIRS. MAYBE A CAR SO I CAN DRIVE MYSELF.

MORE MONEY FOR SOCIAL ENJOYMENT, TO TRAVEL TO SEE MY GRANDCHILDREN.

MONEY, I DO NOT GET ENOUGH MONEY FOR CLOTHING OR GROCERIES \$447 PER MONTH TO PAY BILLS AND GROCERIES, TRANSPORTATION, SOME MEDICINE, ETC.

SOMEONE TO HELP ME GO FOR WALKS.

I COULD DO MORE SPORTS OR SOMETHING ELSE. IT COST TOO MUCH FOR TAXIS.

HIGHER EDUCATION.

MORE FINANCIAL AID, FOR THINGS LIKE PRESCRIPTIONS, SOME EQUIPMENT, LIKE A BRACE FOR MY KNEE WITH ARTHRITIS.

MONEY FOR TRAVEL

TRANSPORTATION EXPENSES FOR SOCIAL EVENTS.

WITH THE PROGRAM I ALREADY GET EVERYTHING I WANT AND NEED.

MONEY TO GET GRASS CUT.

MONEY.

FUNDING TO GO TO LAW SCHOOL. I FEEL REALLY RESTRICTED ABOUT THE WHOLE PROGRAM, IT WILL ONLY FUND MY B.A. WHEN A PERSON SETS THEIR GOALS, FUNDING FOR EDUCATION SHOULD BE PROVIDED, OTHERWISE MY LIFE WILL BE RESTRICTED. THE DSP PROGRAM IS TELLING ME WHAT I CAN AND CANNOT DO.

MORE TRAVELLING ALLOWANCE, I HAVE A LIMITED AMOUNT OF FUNDS TO GO TO HOSPITAL, AND IT IS NEVER ENOUGH.

COMPUTER

PEOPLE LIKE MYSELF, LIVING WITH RELATIVES, THAT THERE WOULD BE MORE FUNDING FOR THE CAREGIVERS! BY LIVING AT HOME, I AM HAVING A FAMILY MEMBER ASSIST ON A 24 HOUR BASIS, AND THEY DO NOT GET ANYTHING FOR THEIR TIME. IF I WAS LIVING OUT ON MY OWN, I WOULD NEED A LOT MORE ASSISTANCE THAN I PRESENTLY RECEIVE, THEREFORE THERE SHOULD BE MORE LEEWAY IN REGARDS TO CAREGIVERS.

HOMEMAKER TO COME IN EVERY SECOND DAY.

IT WOULD BE TO HAVE SOMEONE TO CALL WHEN I AM LONELY. JUST TO CHAT WITH WHEN MY HUSBAND IS AT WORK AND MY FRIENDS ARE AT WORK.

WINTER TRANSPORTATION, AS I ONLY HAVE A BIKE TO RIDE. CAREGIVER TO TAKE ME PLACES.

EMPLOYERS TO HIRE ME WITH MY DISABILITY, GIVE ME A CHANCE, A JOB.

A BIGGER BATHROOM.

MONEY FOR KIDS SNACKS AND CLOTHING, WHEN YOU ONLY HAVE \$24 FOR THAT FOR THE MONTH IT IS HARD. MONEY FOR PERSONAL THINGS LIKE PADS AND UNDERWEAR, IT IS NOT MUCH.

SUPPORT GROUP WITH PEOPLE WITH THE SAME DISABILITY.

BATHROOM OFF THE BEDROOM.

SCOOTER, WITH A BUTTON THAT COLLAPSES AND YOU CAN PUT IT IN THE TRUNK OF YOUR VEHICLE.

MONEY TO PURCHASE CLOTHING.

MONEY FOR PROGRAMS, WE HAVE TO TAKE IT OUT OF OUR OWN POCKET! I CANNOT GO BACK INTO PROGRAMS, BECAUSE I WOULD NOT PAY FOR IT MYSELF.

NOTHING JUST YET. I AM SURE THAT WILL CHANGE, EVENTUALLY, I WILL NEED A WHEELCHAIR PROBABLY.

MONEY, YOU CANNOT DO ANYTHING WITHOUT MONEY. I CAN HARDLY PAY FOR MY INSURANCE OR GAS.

TO SEE MY FRIEND [] AGAIN.

MORE FINANCIAL ASSISTANCE FOR SOCIAL ACTIVITIES AND FOR THE EXTRAS, WE ARE BARELY MAKING ENDS MEET ON OUR FIXED INCOME, DUE TO THE EXTRA FINANCIAL BURDEN DUE OF THE ILLNESS.

PAID CAREGIVER TO HELP ME GO TO SOCIAL ACTIVITIES AND MONEY FOR THOSE THINGS.

HAVE A WHEELCHAIR ACCESSIBLE VAN FOR TRANSPORTATION

HAVING SOMEONE DEAL WITH MY DISABILITY AND THE SYSTEMIC CORRUPTION IN THE SYSTEM.

TRANSPORTATION IS EXPENSIVE.

GET A BETTER JOB - I TOOK THE ELECTRICIANS COURSE BUT NO ONE WILL HIRE ME WITH THE SEIZURES.

THAT MY ROOMMATE AND I COULD BOTH GO OUT AT THE SAME TIME, BECAUSE I LIKE TO HAVE SOMEONE TO GO OUT WITH.

GETTING IN AND OUT OF MY CAR MYSELF. I CANNOT GET IN AND OUT MYSELF, I NEED A DIFFERENT LIFT,

TO BE ABLE TO DRIVE

A POWER CHAIR.

PROXIES

QUESTION: IF < PFNAM > COULD RECEIVE ONE NEW SUPPORT OR MORE OF A SUPPORT THAT IS CURRENTLY BEING RECEIVED THAT WOULD MAKE YOUR or < PFNAM >'s LIFE BETTER, WHAT WOULD IT BE?

RESPIRE CARE - NONE IS BEING RECEIVING NOW.

SPEECH THERAPY, MORE OF IT, AT \$60 PER HOUR WE CA NOT PAY FOR AS MUCH AS WE WANT. PARENTS NOW PAY FOR ALL OF IT.

PAID CAREGIVER TO TAKE HIM TO SOCIAL THINGS.

I THINK ABA THERAPY WOULD BE GREAT.

BETTER QUALITY SERVICES IN ALL AREAS, BOTH QUANTITY AND QUALITY.

I THINK ONE OF THE DRAWBACKS FOR [] AND MYSELF IS FOR HER TO GET OUT. DUE TO TRANSPORTATION PROBLEMS SHE IS UNABLE TO ATTEND SWIMMING AND BOATING AND THINGS. TRANSPORTATION TO GET HER INVOLVED IN OTHER ACTIVITIES WOULD BE A USEFUL THING. I, MYSELF HAVE LOTS OF MEDICAL PROBLEMS AND CANNOT DRIVE A VEHICLE SO IT IS HARD FOR ME TO GET HER THERE. WE ONLY HAVE ONE VEHICLE AND MY HUSBAND USES IT FOR WORK. HE LEAVES AT AROUND 4:30 AM.

SPEECH THERAPY.

I WOULD SAY MORE FUNDING FOR SOCIAL OUTINGS.

SOMEBODY TO PICK HER UP FOR EVEN ONE AFTERNOON A MONTH, TO TAKE HER TO SUMMERSIDE FOR TEA OR SOMETHING. I THINK SHE WOULD LIKE THAT.

GETTING A BIT MORE FOR CLOTHING AND BEDDING WOULD BE A HELP. THINGS ARE PRETTY GOOD OTHER THAN THAT I DO NOT WANT TO COMPLAIN. I APPRECIATE EVERYTHING THEY GIVE ME BUT A LITTLE MORE MONEY WOULD BE A GREAT HELP.

IT IS JUST THE MONEY ITSELF BECAUSE IT COSTS A LOT FOR ALL OF THE PROGRAMS THAT SHE IS IN.

AT THE MOMENT HE GETS ENOUGH SUPPORT.

MORE CONTACT WITH FAMILY, THAT IS WHAT HE WOULD ENJOY MORE THAN ANYTHING.

I AM NOT GREEDY, I WOULD JUST LIKE TO SPEND A LITTLE MORE ON HER.

MORE FINANCIAL AID.

SOMEONE TO TAKE HIM OUT IN THE AFTERNOON TO DO THINGS WITH HIM, BECAUSE HE REALLY DOES NOT HAVE ANY FRIENDS, SO HE WOULD REALLY ENJOY THAT.

IT WOULD BE NICE IF THERE WERE MORE PROGRAMS OR THINGS SHE COULD TAKE PART IN.

MORE SOCIAL OPPORTUNITY & ONE-TO-ONE SUPPORTS. HE ONLY RECEIVES \$32 PER MONTH FOR THAT, SO IT IS LIMITED. IF HE GOES OUT FOR A SOCIAL ACTIVITY, HE HAS TO PAY AT LEAST \$10 PER HOUR FOR 3 HOURS FOR THE PAID CAREGIVER TO GO WITH HIM, SO IT IS ALL SPENT ON THAT. FUNDS FOR THE ACTIVITY ITSELF AND FOR THE COST OF TRANSPORTATION HAVE TO COME FROM HIS OTHER MONIES, OTHER THAN DSP MONIES. SO IT LIMITS HIM TO ONLY GETTING OUT ONCE PER MONTH. IT IS CERTAINLY NOT SUFFICIENT FUNDING.

MORE RESPITES, HE REALLY ENJOYS GOING THERE. HE IS GOING TO A DAY CAMP IN THE SUMMER. HE IS ONLY GOING ONE DAY A WEEK BUT HE PROBABLY WOULD ENJOY GOING A LOT MORE. WE ARE ALSO RECEIVING MONEY FOR HIM TO GO OUT WITH A BUDDY AND HE WOULD PROBABLY ENJOY TO DO THAT A LITTLE MORE.

I WOULD LIKE TO SEE [] MORE INVOLVED WITH SPECIAL SPORTS PROGRAMS.

A CAREGIVER.

MORE PLACES WHERE HE COULD GO AND MEET OTHER PEOPLE.

RESIDENTIAL AID FOR [] TO LIVE ON HIS OWN NEAR US.

PROBABLY FOR SOME OF THE SIBLINGS TO OFFER TO TAKE HER SOMEPLACE ONCE IN A WHILE.

WE ARE QUITE HAPPY WITH THE SUPPORT THAT SHE GETS NOW, BUT IT WOULD BE GREAT FOR HER TO BE ABLE TO GET OUT MORE OFTEN.

NOTHING REALLY.

NEED HELP WITH SPECIAL FOOD.

MORE FINANCIAL AID.

HE NEEDS SPEECH THERAPY AND SUPERVISION FOR HIS ADA PROGRAM.

TRYING TO UNDERSTAND THE DISABILITY MORE AND TREATMENT METHODS AND HOW TO DEAL WITH IT.

RESPIRE AND QUALIFIED SERVICES.

WE NEED MORE PEOPLE TRAINED IN BEHAVIOURAL INTERVENTION IN SCHOOL OR HOME.

A NEW MATTRESS ON OUR BED.

ANGER MANAGEMENT

I WOULD LIKE TO SEE HIM HAVE A TUTOR FOR HIS EDUCATION.

IF WE WERE GETTING A LITTLE MORE MONEY WE COULD GO AWAY TO NOVA SCOTIA ONCE A YEAR OR PLACES OTHER THAN ON THE ISLAND THAT THEY WOULD ENJOY THEMSELVES. LIKE A REAL VACATION.

I WOULD LIKE TO BE ABLE TO TAKE THEM AWAY FOR A HOLIDAY. AWAY FROM THE SAME ROUTINE OF THE ISLAND. IT WOULD BE NICE FOR US ALL.

I WOULD LIKE FOR HIM TO HAVE A BIG BROTHER, I THINK THAT THAT WOULD BE GOOD FOR HIM.

RESPIRE CARE, ONE-ON-ONE SUPPORT TO TAKE HER TO SOCIAL THINGS.

AN AIR CONDITIONER.

SOME MORE SERVICES ON PEI WOULD HELP A LOT.

JUST TO GET MORE SUPPORT IN SCHOOL. [] HAS A DIFFICULT TIME WITH SOME THINGS BUT NOW THAT HE IS IN HIGH SCHOOL IS HAS BEEN HAVING SEVERE PROBLEMS. IT IS A MATURITY THING TOO THOUGH.

SOME KIND OF SUMMER PROGRAM FOR HIM. BY THE END OF THE SUMMER HE HAS NOTHING TO DO. ONE ON ONE SWIMMING LESSONS OR SOMETHING LIKE THAT. SOMETHING TO DO WITH SPORTS OR CAMPS.
DENTAL - PLATE REPLACEMENT IS VERY OLD.

MORE MONEY FOR CLOTHES, THEY DO NOT GIVE YOU MUCH.

ONE ON ONE SUPPORT OR HELP WITH TRANSPORTATION SERVICES.

FOR HIM TO HAVE MORE ONE ON ONE SUPPORT. RIGHT NOW HE HAS SOMEONE THAT COMES AND TAKES HIM OUT ONCE A WEEK, BUT I THINK HE WOULD DO REALLY WELL IF HE HAD A COUPLE OF DAYS A WEEK INSTEAD OF JUST ONE. IT WOULD HELP ME AS WELL.

A LITTLE MORE MONEY FOR HER ENTERTAINMENT BECAUSE IT GET IS TIGHT FOR HER, ESPECIALLY IF SHE HAS TO PAY FOR TRANSPORTATION TO ACTUALLY GO SOMEWHERE.

PLANNED PROGRAMS OR ACTIVITIES AND/OR MORE HOURS FOR YOUTH WORKER SO SHE THAT SHE KEEPS BUSY AND DOES NOT GET BORED OR DEPRESSED.

I WOULD LIKE TO SEE AN EXTRA WEEKEND OF RESPITE CARE A MONTH, IT WOULD LIKELY BE BENEFICIAL TO BOTH [] AND OURSELVES. [] SHOULD BE PUT INTO A GYM WITH TRAINED PERSONS SO THAT HE COULD USE SOME OF THE RESTLESS ENERGY.

MY HEALTH IS NOT THAT GOOD, I SUPPOSE A LITTLE MORE MONEY COULD NOT HURT. I HAVE NO TRANSPORTATION MYSELF, I RELY ON MY DAUGHTER AND DAUGHTER-IN-LAW TO GET ME AROUND TO WHERE I NEED TO GO WHENEVER I NEED TO GO.

SOCIALIZATION. SHE NEEDS IT TO HAVE FREEDOM TO DO THINGS, WITHOUT THAT SUPPORT SHE IS PUT INTO A RISK AND IS UNABLE TO DO THAT.

ACCESS TO A FAMILY OR SOME GROUND ROUTES. SOMEONE COMMITTED TO BE HER FAMILY. LIKE A RESPITE FAMILY THAT SHE COULD CALL HER OWN THAT WOULD MAKE A BIG DIFFERENCE TO HER.

AGAIN IT WOULD BE SOCIALIZATION. THERE ARE SO MANY THINGS HE COULD TAKE PART IN BUT IS UNABLE AT THIS TIME.

IT WOULD BE MORE FUN MONEY. SHE IS IN HER 50'S AND THE ONE THING THAT IS MISSING IN HER LIFE ARE THE LEISURE ACTIVITIES.

SUPPORT FOR ACTIVITIES FOR [].

MORE FINANCIAL HELP - SOCIAL THINGS, CAMPING, THINGS LIKE THAT.

PROBABLY A LITTLE MORE HELP OVERALL, I FIND IF SHE GOES TO RESPITE, IT IS 90\$ FOR A WEEKEND, AND TO ME THAT IS A LOT. HER CHEQUE COMES ON THE FIRST, AND THEN THE CAMP IS ON THE 19TH, SO SOMETIMES I FIND IT HARD TO GET HER TO HER CAMP. IT IS A SHORT WEEKEND FOR THEM AND A SHORT ONE FOR ME, THEY USED TO BE 9 DAYS NOW IT IS DOWN TO 5 DAYS.

THE SUPPORTS JUST BEGAN IN APRIL, AND WE ARE SO HAPPY WITH THAT RIGHT NOW THAT I CANNOT THINK OF ANYTHING ELSE HE NEEDS RIGHT NOW.

MEDICAL EXPENSES.

MEDICAL COVERAGE FOR EYE GLASSES, DENTAL WORK, AND DRUGS IF HE NEEDED THEM.

WE ARE ACTUALLY LOOKING INTO GETTING HIM A NEW IMPLANT THAT IS ON HIS EAR INSTEAD OF HIM HAVING THE BODY PROCESSOR.

I WOULD SAY THE SUMMER CAMP. IT HAS TO COME OUT OF OUR OWN POCKET. IT IS EXPENSIVE AND TWO CHILDREN GOING IS 100\$ AND I CANNOT AFFORD IT.

RESPITE CARE. HE IS AT THE HIGH END OF THE RESPITE CARE SCALE AND IT WOULD BE HELPFUL TO RECEIVE A LITTLE MORE. I REALIZE THEY ARE DOING AS MUCH AS THEY CAN THOUGH.

REALLY NOTHING THAT I CAN SEE.

CHILD CARE

HAVING SOMEBODY WHO COULD COME AND PICK HER UP AND TAKE HER PLACES (LIKE BOWLING, OR TO THE MOVIES,

ETC), WHO WOULD BE COMFORTABLE AROUND HER, AND WHO SHE WOULD BE COMFORTABLE AROUND

MORE MONEY FOR PERSONAL SOCIALIZATION SUPPORTS AND MORE ACCESS TO THE COMMUNITY WITH SUPPORTS.
MORE SOCIAL ACTIVITIES.

WE HAVE TO MAKE QUITE A FEW TRIPS TO HALIFAX FOR DOCTORS APPOINTMENTS, IT WOULD BE NICE IF THEY WERE FULLY COVERED INSTEAD OF JUST PARTIALLY.

NEW DENTURES

I GUESS IT WOULD BE MORE SUPPORT SYSTEMS- I WOULD SAY IF HE HAD MORE OUTSIDE CONTACT, IF THERE WAS MORE MONEY AVAILABLE FOR MORE OUTSIDE CONTACT- PROGRAMS THAT HE COULD MAKE FRIENDS IN- MONEY FOR HIM TO GO TO A SHOW, SOMEONE TO GO WITH INSTEAD OF MY HUSBAND AND I. WE WERE SUPPOSED TO HAVE THAT LAST WINTER, BUT IT WAS PULLED B/C HE WENT BACK TO SCHOOL.
MORE SOCIAL ACTIVITIES AND EXERCISES PLANNED.

MORE SPEECH AND LANGUAGE THERAPY.

TRANSPORTATION TO AND FROM TREMPLOY. GETTING THERE IS A BIG TRIP FOR ME.

COMPUTER AIDS

MEDICATION, EYE GLASSES AND EYE DOCTOR APPOINTMENTS TO BE COVERED UNDER DSP

WE ARE SATISFIED WITH WHAT WE ARE GETTING.

GETTING MORE HELP WITH HER LEARNING.

WHEELCHAIR ACCESSIBLE VAN WITH A CHAIR LIFT.

RESPIRE CARE, A NUTRITION PROGRAM, ALSO I WOULD LIKE TO SEE HER PHYSICAL ACTIVITY INCREASE, IT IS LIMITED IN PART BECAUSE THE PROGRAMS ARE HERE FOR HER TO TAKE PART IN.

WE WOULD REALLY LIKE IT IF SHE COULD GET MORE SPEECH THERAPY. IT IS HARD BECAUSE SOMEONE WITH HER DISABILITY SHOULD BE SEEING A SPEECH THERAPIST AT LEAST 3 TIMES A WEEK, BUT THE THERAPIST IS IN TOWN, SO IT IS QUITE A BIT OF TRAVELING SO SHE ONLY GOES TWICE. ALSO, THE DSP ONLY COVERS HALF OF THE COST, IT WOULD BE GREAT IF THEY WOULD COVER MORE.

MORE RESPIRE CARE.

HELP WITH SPEECH THERAPY.

HELP TO FIND EMPLOYMENT FOR [] BECAUSE SHE DESPERATELY WANTS TO WORK.

MUSICAL PROGRAM, HE ENJOYS PLAYING MUSIC, HARMONICA AND THE ORGAN AND HE PLAYS THEM QUITE WELL.

MORE RESPIRE CARE.

INCREASE ONE TO ONE SUPPORT.

A FRIENDSHIP CIRCLE FOR []

IF I COULD RECEIVE MORE FINANCIAL FUNDING TO DO MORE FUN THINGS WITH HIM.

SPEECH THERAPY.

IF I HAD A LIST OF PEOPLE WHO DID RESPIRE, THAT WOULD MAKE LIFE EASIER. I JUST DO NOT KNOW WHO TO ASK AND I DO NOT KNOW MUCH ABOUT THE PROGRAM, SO A LIST WOULD MAKE LIFE EASIER.

SPECIAL ACTIVITIES AND/OR DAY CAMPS FOR KIDS WITH HEARING IMPAIRMENTS.

I HAVE NEVER THOUGHT OF IT, MAYBE MORE TRANSPORTATION AVAILABILITY.

A BIT MORE FINANCIAL SUPPORT FOR THINGS LIKE GLASSES.

SOME SOCIAL ACTIVITIES FOR [] TO TAKE PART IN.

A PERSON TO COME AND TAKE HER TO DO SOMETHING AND TO HANG OUT WITH [] OTHER THAN HER MOTHER.

I THINK IT IS PRETTY GOOD THE WAY IT IS, SO LONG AS IT STAYS THE WAY IT IS.

I THINK HE WOULD LIKE TO GO SWIMMING MORE AND BECAUSE I DO NOT DRIVE, IT IS DIFFICULT SINCE HIS FATHER HAS BEEN QUITE UNWELL DURING THE PAST YEAR.

A LITTLE MORE TRAVELING.

PROBABLY FOR ME IT WOULD BE MORE RESPITE CARE, I AM GETTING OLDER, AND EVERY WEEKEND WOULD BE LOVELY.

SHE WOULD LIKE A LITTLE MORE FINANCIAL AID.

I THINK A LITTLE MORE MONEY WOULD HELP HIM TO BE ABLE TO GET THINGS FOR HIMSELF.

DENTAL AND MEDICAL SUPPORT FOR [].

HE NEEDS MORE HELP WITH HIS SPEECH WHICH IS LIMITED. IF HE COULD EXPRESS HIMSELF BETTER, WE COULD FIND OUT HOW MUCH HE IS CAPABLE OF LEARNING.

PROBABLY, SOMEONE MORE KNOWLEDGEABLE IN THE FIELD TO WORK WITH US.

I AM QUITE HAPPY WITH WHAT SHE IS GETTING NOW.

MORE FINANCIAL SUPPORT.

MORE ONE ON ONE SUPPORT AND TRANSPORTATION SERVICES.

TRANSPORTATION ASSISTANCE TO MAKE IT AFFORDABLE.

TRANSPORTATION AND A ONE ON ONE WORKER.

A ONE ON ONE WORKER.

A PERSON THAT COULD BE AROUND TO TAKE [] PLACES WHEN I AM UNABLE TO AND A LITTLE MORE FINANCIAL SUPPORT SO SHE CAN GET OUT MORE. I HAVE CANCER IN MY LEG SO IT IS NOT ALWAYS EASY.

A CIRCLE OF FRIENDS, I THINK EVERY CHILD WITH DOWNS SYNDROME SHOULD HAVE THIS SUPPORT.

MORE THERAPY, IBI THERAPY IS WHAT HE RECEIVES, AND IT TEACHES HIM HOW TO TALK HOW TO PLAY AND ALL THOSE THINGS THAT REGULAR CHILDREN WILL LEARN BY OBSERVING, HE ONLY GETS TWENTY HOURS A WEEK AND I THINK THAT HE SHOULD GET MORE.

MORE FINANCIAL SUPPORT SO THAT HIS MOTHER CAN STAY HOME AND TAKE CARE OF HIM.

IF SOME PROGRAM WAS OFFERED TO INDIVIDUALS LIKE [] DURING THE EVENING, JUST FOR HIM TO BE SOCIAL.

RIGHT NOW WE ARE PRETTY HAPPY WITH WHAT WE GET.

MORE SUPPORTS FOR EVENING RECREATION.

IF SHE COULD BE OUTSIDE AND WITH PEOPLE MORE. RIGHT NOW SHE IS GONE 3 TIMES A WEEK AND SHE LOVES BEING OUT AND AROUND. 3 DAYS IS GREAT, BUT IT WOULD BE EVEN BETTER IF IT WAS 5 DAYS A WEEK, I KNOW SHE WOULD LOVE THAT.

WOULD LIKE FOR [] TO HAVE FIVE DAYS A WEEK INSTEAD OF FOUR DAYS A WEEK WITH HER WORKER.

A MALE ROLE MODEL.

PROBABLY MORE INTO RESPITE CARE.

HE NEEDS MORE SUPPORT, LIKE TUTORING TIME IN THE SUMMER.

RESPIRE CARE, FOR WHEN I AM NOT HERE.

MORE FINANCIAL SUPPORT BECAUSE IT IS GETTING HARD TO MAKE ENDS MEET, I WORK ALL THE TIME AND I STILL CANNOT GET HIM EVERYTHING HE NEEDS, OR EVEN EVERYTHING HE SHOULD HAVE.

MORE RESPIRE CARE, OR A SOCIAL ACTIVITY FOR [] TO GO TO EVEN IF IT WAS JUST FOR THE WEEKEND.

IT WOULD BE THE PART WHERE THEY HAVE THE RESPIRE CARE WORKERS, THEY SHOULD BE PAID FOR TAKING HER PLACES. THE PROGRAM GIVES US MONEY TO PAY THE RESPIRE CARE WORKER, BUT WHEN SHE TAKES [] OUT TO DO THINGS, SHE HAS TO PAY FOR THE ACTIVITIES AND THAT JUST CANCELS OUT WHAT SHE IS GETTING OUT OF THE PROGRAM. IT MAKES IT DIFFICULT TO KEEP A RESPIRE CARE WORKER BECAUSE THEY ARE BASICALLY VOLUNTEERING THEIR TIME. IT IS HARD ON [] BECAUSE SHE WILL JUST START GETTING USED TO SOMEONE AND THEN THEY LEAVE, AND WE HAVE TO START ALL OVER AGAIN.

A BIG BROTHER OR BIG SISTER, THAT KIND OF THING, SOMEONE TO TAKE HER OUT.

A LITTLE BIT MORE HELP WITH TRANSPORTATION SERVICES.

IT WOULD BE NICE IF [] AND I HAD SOME OF OUR INDEPENDENCE. WE HAVE TO LOOK AFTER HIM 24-7, EVEN JUST A LITTLE TIME TO GET AWAY. Q60- HE IS WORKING FOR 7.70/HR, BUT WE HAVE TO PAY HIS WORKER THAT GOES WITH HIM \$15/HR, DSP PAYS FOR ABOUT 56% OF THAT, AND WE PAY THE REST. SO, WE ACTUALLY PAY FOR HIM TO WORK, BUT IT IS MORE LIKE A SOCIAL ACTIVITY FOR HIM MORE THAN ANYTHING.

SITTER SERVICES BECAUSE WE CANNOT LEAVE HIM ALONE.

I AM HOPING THESE TWO GENTLEMEN, THAT WILL START COMING IN THE SUMMER, WILL TAKE HIM OUT SO HE CAN GET OUTSIDE THE HOME. BUT IT IS NOT THE SAME AS REGULAR 13 YEAR OLD FRIENDS TO TAKE HIM OUT.

IT WOULD BE TO HAVE A SITTER FOR [] WHEN I HAVE TO GO OUT AND TAKE MY SON TO A BALL GAME IN CHARLOTTETOWN OR SOMEWHERE. [] DOES NOT LIKE CHANGE IN HER ROUTINE SO IT IS DIFFICULT, I HAVE TO CANCEL GAMES SOMETIME BECAUSE OF IT.

A LIST OF PEOPLE OUT THERE LIKE [] SO INTERACTION WITH OTHERS WOULD BE POSSIBLE AND ATTAINABLE.

A SUNDAY WORKER TO HELP HIM ON SUNDAY AS WELL.

HAVE SOMEONE TO STAY OVERNIGHT WITH HIM. HIS WORKER STAYS UNTIL 10 PM, BUT I THINK IT WOULD BE BETTER IF HE HAD SOMEONE TO STAY OVERNIGHT WITH HIM.

SOME KIND OF DAY CARE SERVICE FOR WHEN HE IS IN SCHOOL, I COULD GO BACK TO WORK. RIGHT NOW THERE IS REALLY NO PLACE TO TAKE HIM AND IT DOES GET HARD WHEN YOUR LIVING ON ONE SOURCE OF INCOME.

RESPIRE CARE, VERY BADLY NEEDED, I HAVE NO RESPIRE CARE WHATSOEVER AND I LOOK AFTER HIM 24 HOURS A DAY, YEAR IN AND YEAR OUT. IT IS VERY DIFFICULT.

MORE OF THE SAME SUPPORTS THAT I AM RECEIVING NOW WOULD BE BETTER.

I AM HAPPY WITH WHAT I AM GETTING. I HAVE MOST OF WHAT WE NEED.

FINANCIAL AID FOR HIS INTENSIVE BEHAVIORAL INTERVENTION, AND FUNDING FOR DAY CARE.

FINANCIAL AID FOR MORE ABA AND SOCIAL PROGRAMS.

IF SHE/DSP COULD HELP PAY FOR THE RENT. SHE IS 26 AND I DO NOT MIND PAYING ALL OF THE RENT MYSELF, BUT IT WOULD MAKE THINGS A LOT EASIER IF WE COULD GET SOME HELP WITH IT. THEY WILL PAY \$1200 PER MONTH FOR HER TO STAY IN A GROUP HOME, BUT THEY WILL NOT GIVE ME \$50 EXTRA A MONTH TO HELP OUT WITH THE RENT HERE.

I AM QUITE HAPPY WITH THE WAY THINGS ARE GOING NOW WITH THE SPORTS, AND DANCES IN THE WINTER AND SWIMMING. THERE IS SO MUCH NOW. I JUST HOPE IT STAYS THAT WAY.

A RAMP FOR THE FRONT DOOR SO HE CAN GET IN AND OUT EASIER.

I DO NOT HAVE ANYONE TO TAKE HER FOR RESPITE, I HAVE SOME DAUGHTERS, BUT ONE DAUGHTER HAS A CHILD WITH CEREBRAL PALSY, ALSO SHE IS A [] SO SHE IS EXTREMELY BUSY. THE OTHER DAUGHTER TAKES HER AS MUCH AS SHE CAN BUT I STILL COULD USE A LITTLE MORE HELP. JUST GENERALLY THE BIGGEST SUPPORT WOULD BE A LIST OF THE RESPITE WORKERS AVAILABLE.

THAT LITTLE BIT OF EXTRA MONEY GIVES HER A LITTLE BIT MORE FREEDOM. LIKE IF SHE WANTED TO GO TO CHARLOTTETOWN, AND THERE WAS NO ONE AVAILABLE TO TAKE HER, SHE COULD CALL ONE OF HER FRIENDS AND OFFER TO PAY THEM TO TAKE HER IN, AND THAT MAKES THINGS A LOT EASIER.

A PROGRAM THAT [] COULD GO TO WITH OTHER PEOPLE WITH DISABILITIES. SOME SOCIAL ACTIVITIES.

MORE FINANCIAL AID.

WE NEED SOME REMODELING OF THE BATHROOM, A LARGER BATHROOM.

WE HAVE HAD HER SINCE MY HUSBANDS FATHER DIED BEFORE SHE TURNED 18. MY HUSBANDS IS ON CPP AND IT IS KIND OF ROUGH FINANCIALLY, BUT WE TRY TO MAKE. I WOULD LIKE A LITTLE MORE HELP.

RESPITE CARE.

MORE MONEY FOR CHILD CARE AND RESPITE, ALSO TRAVELING EXPENSES. I DO NOT UNDERSTAND HOW SOME PEOPLE CAN GET FUNDING IF THEY NEED TO GO TO THE OTHER SIDE FOR A MEDICAL APPOINTMENT OR AN OPERATION, AND I CANNOT.

MONEY FOR RECREATIONAL ACTIVITIES, SO WE CAN AFFORD TO TAKE [] OUT MORE.

COMMUNITY ACCESS - PEOPLE TO TAKE HER OUT FOR SOCIAL THINGS.

RESPITE CARE WOULD HELP.

AT THE MOMENT HIS HOUSING IS CONDEMNED, AND WE ARE ARRANGING A MEETING WITH SOCIAL SERVICES FOR HIM. SOMETHING TO HELP WITH HIS TRANSPORTATION COSTS AS WELL.

I WOULD LIKE TO SEE HER IN THE QCRS PROGRAM MORE, IT WOULD HELP HER TO BE MORE ACTIVE, MAYBE DROP SOME MORE WEIGHT. SHE HAS BEEN INVOLVED IN THE QCRS PROGRAM DURING THE DAY, TWICE A WEEK, AND LOVES IT. THEY DO DIFFERENT THINGS IN THE COMMUNITY. SHE IS ALSO INVOLVED IN TREMPLOY, AND HAS BEEN WORKING THERE FOR ALMOST 18 YEARS. SHE MAY ONLY RECEIVE \$10 EVERY FEW WEEKS OR SO, BUT IT IS GREAT FOR HER.

I GUESS MAYBE MORE MONEY FOR THE CARE HE RECEIVES AT HOME, BECAUSE IT IS HARD FOR ME TO DO IT 24/7.

HAVING SOMEONE TO TAKE HIM AROUND TO DIFFERENT PLACES AND FUNCTIONS, BECAUSE WE HAVE NO VEHICLE.

HELP ME PAY FOR THE DENTIST. ANY OTHER SPECIAL NEED, CAREGIVER FOR WHEN I AM NOT AVAILABLE OR AM AWAY.

FOR HIM TO GET OUT MORE, THAT WOULD BE A GOOD THING.

FOR ME TO GET A BREAK NOW AND AGAIN FROM TAKING CARE OF [].

SERVICES SPECIFICALLY FOR AUTISTIC PEOPLE.

I THINK MORE OPPORTUNITIES FOR SOCIALIZATION, MY CONCERN IS WHAT IS GOING TO HAPPEN WITH HER AFTER SCHOOL ENDS, SHE WILL BE ABLE TO DO THAT UNTIL SHE IS 21, BUT SHE WANTS TO BE LIKE EVERYONE ELSE AND NOT BE IN SCHOOL UNTIL SHE IS 21. I WOULD LIKE TO FIND SOME SOCIAL OPPORTUNITIES FOR HER AND PERHAPS SOME WORK DOWN THE ROAD. Q30- RIGHT NOW, I HIRE A 16 YEAR OLD TO LOOK AFTER HER, BUT AS SHE GETS OLDER, I WILL NOT BE ABLE TO HIRE SOMEONE THAT AGE THAT WILL WORK FOR \$7-10/HR. I WILL HAVE TO PAY THEM MORE, SO THAT WILL BE HARD FINANCIALLY FOR ME. IT IS HARD TO FIND ADEQUATE PEOPLE TO LOOK AFTER HER.

RESPITE CARE AND CLOTHING ALLOWANCE.

WELL FOR US IT WOULD BE RESPITE CARE. I GUESS THE OTHER THING WOULD BE CLOTHING ALLOWANCES.

MORE OF A FINANCIAL SUPPORT WOULD BE GOOD.

MONEY TO COVER VACATION TIME FOR US TO BE ABLE TO GO ON VACATION. IT WOULD BE LIKE RESPITE CARE WITH HIS FAMILY AND I THINK HE WOULD REALLY ENJOY THAT AND IT WOULD MAKE HIM HAPPY.

MORE SERVICES TO HELP WITH TRANSPORTATION FOR [].

IF SHE COULD GET A LIFT FOR THE FRONT STEPS, SO THAT SHE CAN GET IN AND OUT OF THE HOUSE WITHOUT MUCH DIFFICULTY.

RESPITE CARE, QUALIFIED RESPITE CARE. A PLACE FOR HIM TO BE WITHOUT HAVING HIM HOSPITALIZED. KNOWING THAT WHEN WE ARE NO LONGER HERE, OR UNABLE TO CARE FOR HIM, THAT HE WILL BE CARED FOR PROPERLY.

AN INCREASED LIVING ALLOWANCE EQUAL TO WHAT WE WOULD GET IF WE WERE WITH QCRS.

MORE PROVISION FOR TRANSPORTATION & FOR DRUGS THAT ARE NOT COVERED NOW THAT WERE COVERED BEFORE, PUT THAT BACK IN PLACE.

MORE ONE ON ONE SUPPORT.

MORE ONE ON ONE SUPPORT FOR [].

MORE ONE TO ONE SUPPORT.

MORE SOCIAL INTERACTION WITH PEERS FOR [].

SOCIAL SPENDING FOR HER LIFE.

I WOULD LIKE TO SEE MORE ONE ON ONE SUPPORT IN THE EVENINGS.

MORE INTERVENTION WITH OTHER CHILDREN, HE GETS HIS ONE ON ONE WITH A THERAPIST, AND IN THE WINTER GOES TO DAYCARE. HE HAS GONE TO PLAYSCHOOL BEFORE AND THAT REALLY HELPED.

SOCIAL ACTIVITIES, PAID PROGRAMMING OR FAMILY HAPPY FUN THINGS THAT WE ALL CAN DO TOGETHER.

MORE CAMP TIME FOR [].

SOCIAL MONIES FOR ACTIVITIES LIKE MOVIES OR SOMETHING LIKE THAT.

WE ARE GOING TO NEED RENOVATIONS TO OUR HOUSE IN ORDER FOR [] TO LIVE HERE. I WOULD LIKE TO HAVE RENOVATIONS DONE AT NO EXPENSE TO US.

MONEY, SOCIAL SPENDING.

MORE THINGS FOR HER AROUND THE YARD, THINGS THAT WOULD BE SAFER, LIKE A FENCE SO ALL THE DOGS CANNOT COME AROUND WHEN SHE IS OUTSIDE, MORE THINGS FOR THE YARD - THINGS LIKE A SWING, OR THINGS FOR HER TO DO IN THE YARD.

THINGS TO DO WITH OUTDOORS, HAVING THINGS FOR [] TO DO OUTDOORS.

SPEECH LANGUAGE PATHOLOGY.

MORE MONEY, OIL BILLS IN THE WINTER.

TRANSPORTATION TO SOCIAL ACTIVITIES & FAMILY GATHERINGS.

DROP IN CENTRE, OR PAID PROGRAMMING FOR A DAY OR EVEN ONCE A WEEK, SO SHE IS NOT BORED AND SO SHE CAN DO THINGS, AND TO GIVE ME SOME TIME ALONE TO DO THINGS.

MONEY, ONLY GETS \$400 A MONTH. CLOTHING, FUN THINGS.

HELP IN FINDING A JOB.

BETTER TRANSPORTATION, SHE GETS SOME TRANSPORTATION MONEY NOW, BUT MORE WOULD NOT HURT.

COMPUTER, SHE WOULD REALLY LOVE TO HAVE ONE.

MONEY TO ALLOW HER TO GO TO DANCES. SHE REQUIRES SOMEBODY WITH HER AT ALL TIMES AND I HAVE PAID SOMEONE TO TAKE HER DANCING. SOME OF THE OTHER GIRLS CAN GO ON THEIR OWN, BUT SHE CAN NOT GO BY HERSELF AND IT IS TOO EXPENSIVE TO HAVE SOMEONE TAKE HER AS MUCH AS SHE WOULD LIKE TO GO.

SHE COULD REALLY USE SPEECH THERAPY. SHE CAN SAY ONLY A VERY FEW WORDS, AND CANNOT USE THE TELEPHONE LIKE THE OTHER GIRLS CAN.

HER HEARING AIDS 2 OF THEM. SHE IS NOT ADJUSTING TO THEM AND IF SHE HAD SOME HELP ADJUSTING TO USING THEM. ALSO, SHE COULD USE WHAT WE USED TO CALL ORTHOPEDIC SHOES TO SUPPORT HER FEET.

MORE RESPITE CARE.

SOMEBODY TO WORK WITH ME IN THE EVENINGS- WITH DSP, I CAN ONLY GET PEOPLE WHEN I AM WORKING. I NEED HELP WHEN HE IS OFF MEDICATION AT NIGHT. WHAT DO YOU DO FOR A TIME OUT? CARRY A 203LB KID UP THE STAIRS? HE EATS AND EATS AND STOGS FOOD DOWN HIS THROAT, AND CHALLENGES ME AND ..I NEED HELP TO KNOW IF THERE IS SOMETHING THAT I AM DOING WRONG...POINTERS TO WORK WITH HIM AND REDIRECT HIM.

A COMPUTER.

MORE SOCIAL THINGS GOING ON, ACTIVITIES, PLANNED EVENTS AND FUN THINGS.

IT WOULD BE NICE FOR HER TO GET 5 DAYS A WEEK IN THE PROGRAM SHE IS IN NOW INSTEAD OF 4. MONEY FOR CLOTHES & SOCIAL ACTIVITIES PLANNED FOR DISABLED.

I GUESS YOU ALWAYS WANT MORE MATERIAL THINGS FOR HER, BUT SHE IS SO HAPPY WITH THE WAY THINGS ARE BECAUSE SHE IS LOVED, HEALTHY AND WELL TAKEN CARE OF. I GUESS JUST MATERIAL THINGS LIKE GOING ON A TRIP SO SHE CAN SEE DIFFERENT THINGS. I WOULD LOVE TO TAKE HER ON TRIPS BUT CANNOT AFFORD TO.

I THINK PROBABLY IT WOULD BE SOMEONE TO COME IN AND DO MORE SOCIAL THINGS WITH HIM.

RECREATIONAL FUNDING, FOR OUTSIDE ACTIVITIES, SPORTS, ETC.

SOMETHING TO HELP IMPROVE HER SELF-ESTEEM AND SELF-CONFIDENCE

SPEECH THERAPY

IT WOULD BE MORE TRANSPORTATION SERVICES.

TRANSPORTATION SERVICES AND RESIDENTIAL SUPPORT.

MORE FINANCIAL ASSISTANCE FOR SITTERS BECAUSE I PAY A HUGE AMOUNT OUT OF MY POCKET.

SOME GOOD TEACHER ASSISTANCE.

MORE RESPITE CARE.

TRANSPORTATION REIMBURSEMENT COSTS TO WORK & RECREATIONAL THINGS. MILEAGE MONIES HAVE NOT CHANGED IN QUITE AWHILE AND THE COST OF GASOLINE HAS REALLY GONE UP.

COMPASSION AND COMMON SENSE. IT WOULD BE EXTREMELY HELPFUL TO RECEIVE MORE FINANCIAL ASSISTANCE. THE COSTS GO HIGHER AS HE GROWS, BUT THE FINANCES STAY THE SAME WITH THE DSP. WITH THE NEW PROGRAM, THE OLDER YOU GET THE LESS MONEY YOU GET. HOW DOES THAT MAKE SENSE. I WOULD LIKE THE PARENTS TO STOP BEING PENALIZED FOR HAVING A DISABLED CHILD. IT IS A LOT LESS COSTLY TO KEEP THE CHILD IN THE HOME WITH THE PARENT AND FAMILY. BUT IN ORDER TO DO THAT YOU MUST ASSIST THE FAMILY WITH THE THINGS THAT ARE SERIOUSLY NEEDED.

MONEY FOR RECREATIONAL ACTIVITIES - THEATRE, MUSIC, SPECIAL EQUIPMENT (TREADMILL), ETC.

IF [] COULD GET A DRIVERS LICENCE.

SOMEONE JUST TO TAKE HIM OUT FOR AN EVENING FOR BOWLING OR POOL OR ANYTHING LIKE THAT, OTHER THAN A FAMILY MEMBER.

IT WOULD BE, FOR ME, I WOULD SAY MORE RESPITE CARE. I HAVE HER 24-7, SO THAT WOULD BE NICE FOR ME. I

KNOW THE WORKER THAT WE HAVE IS EXCELLENT, I AM SATISFIED WITH WHAT WE ARE GETTING. I CAN CALL HER WORKER ANYTIME. I AM REALLY QUITE HAPPY WITH WHAT I HAVE, I AM REALLY GRATEFUL. MAYBE I SHOULD NOT GET MORE RESPITE CARE, I DO NOT WANT TO SEEM GREEDY.

MORE ACTIVITIES OR INVOLVEMENT FOR [] TO PARTICIPATE IN, SOCIAL OR RECREATIONAL ACTIVITIES.

COMMUNICATION DEVICE.

EVERYTHING IS FINE FOR THE TIME BEING.

ONE ON ONE WORKER TO TAKE HER OUT FOR A FEW HOURS A WEEK.

HAVING THE FINANCES FOR HER MEDICAL PROBLEMS/CARE.

MORE FINANCIAL AID.

HELP WITH TRANSPORTATION SERVICES.

THE MONEY TO TAKE HER TO SOCIAL THINGS, LIKE ZOOS, OR THINGS LIKE THAT. MY RETIREMENT INCOME IS NOT MUCH.

MORE FINANCIAL AID AND RESPITE CARE.

THERE NEEDS TO BE SOME MORE ACTIVITIES FOR []

I DO NOT REALLY KNOW, I WOULD LIKE TO SEE HIM GET A HIGHER INCOME FOR HIMSELF. FOR CLOTHES AND THINGS. HE DOES NOT THINK CLOTHING IS VERY IMPORTANT, BUT A LOT OF HIS CLOTHES SHOULD BE THROWN AWAY. SOMEONE TO HELP WITH RESPITE CARE OTHER THAN FAMILY.

RESPITE CARE AND/OR CAREGIVERS THAT ARE QUALIFIED TO LOOK AFTER HIM - FOR WHEN WE CANNOT BE THERE. RIGHT NOW FAMILY DOES IT BUT SOME OF THEM ARE AFRAID IF SOMETHING HAPPENS THEY WILL NOT BE ABLE TO HELP HIM.

RESPITE CARE.

I WOULD SAY RIGHT NOW, WE NEEDED MORE SUPPORT IN HIS DAYCARE, BUT HE DID NOT GET IT. THAT HAD NOTHING TO DO WITH THE DSP THOUGH.

MORE COMMUNITY ACCESS - FOR HER TO HAVE ONE-TO-ONE SUPPORTS MORE OFTEN, A CAREGIVER TO TAKE HER TO SOCIAL EVENTS.

MORE ACCESS TO MONEY FOR HIS EDUCATION.

GETTING SOMEBODY TO BE WITH []

MORE HELP, MONEY FOR TREATS, RECREATION, MOVIE OR THINGS.

SOMETHING THAT WOULD GET [] INTERESTED IN SOME ACTIVITY THAT WOULD TAKE UP SOME MORE OF HIS TIME.

HAVE SOMEONE TO COME AND TAKE [] FOR A LITTLE WHILE TO GIVE ME A LITTLE BIT OF A BREAK

SOMEONE TO COME TO THE HOUSE AND CARE FOR AWHILE WHILE I JUST DO OTHER THINGS.

HELP WITH TRANSPORTATION SERVICES.

SOME SORT OF ACTIVITY SET UP FOR HIM. FOR US TO BE IN A PROGRAM OR SUPPORT GROUP TO SHARE DIFFERENT THINGS LIKE PARENTING STRATEGIES AND FRIENDS FOR [] WITH THE SAME DIFFICULTIES SO HE WOULD NOT FEEL LEFT OUT OR DIFFERENT. ALSO, TO BE INTRODUCED TO PARENTS WHO HAVE ALREADY GONE THROUGH SIMILAR SITUATIONS, KIND OF LIKE A MENTOR. MAYBE EVEN A PERSON TO CALL WHO IS IN THE SAME SITUATION LIKE A CALL BUDDY.

IT WOULD BE GREAT IF THERE WAS SOME KIND OF A SOCIAL PROGRAM WHERE THEY PICKED [] UP AND DID SOME THINGS WITH HIM.

A STEADY JOB FOR []

GROUP MEETINGS TO HAVE FUN. THEY USED TO HAVE ONE ON THE ISLAND, GROUP BOWLING, OR OTHER THINGS FOR THE DISABLED. TO GET THEM OUT OF THE HOUSE TO DO SOMETHING FUN, ORGANIZED SPORTS AND OUTINGS.

FOR OUR FAMILY, IT WOULD BE RESPITE CARE, BECAUSE RIGHT NOW SHE IS NOT GETTING ANY AT ALL. THE REASON FOR THAT IS ANYONE THAT WE HAVE COME INTO CONTACT WITH CANNOT HANDLE [], AND SHERWOOD HOME DOES NOT FEEL THAT THEY CAN LOOK AFTER HER THERE.

SOME HELP WITH THE DRUGS, BECAUSE IT IS THE BIGGEST EXPENSE.

MORE RESPITE CARE

SPEECH THERAPY.

MORE RESPITE CARE

[] COULD USE MORE TIME WITH HIS BROTHER OR FAMILY.

MY LIFE WOULD BE FINANCIAL. [] WOULD BE APPROPRIATE EQUIPMENT SUCH AS SUPPLIES AND MATERIALS FOR IBI, THE CAPABILITY TO MAKE MORE SUPPLIES, A COMPUTER, LAMINATOR, PRINTER, INCREASED FUNDING FOR THE IBI MATERIALS.

I DO NOT THINK IT IS ANYTHING THAT THEY ARE GOING TO GIVE HIM. ACTUALLY, ONE THING THAT I HAVE NOT INQUIRED ABOUT, IS A RAISED TOILET FOR HIM IN ONE OF THE WASHROOMS WOULD BE A HELP. THEY PROBABLY WOULD NOT FIND THAT A PROBLEM.

FULL COVERAGE FOR MEDICATION AND MEDICAL TRIPS, AND ALSO THERE HAS BEEN CUT BACKS WITH HER AIDS

I GUESS IF HE COULD GET OUT OF THE HOUSE MORE IT WOULD BE GOOD.

A PERSONAL FRIEND SHE COULD PLAY WITH, THAT WOULD MAKE HER LIFE BETTER.

BABYSITTING SERVICES FOR []

WE NEED TO DO SOME RENOVATION FOR OUR HOME.

SOMETHING IN THE LINE OF HELP WITH HOMEWORK, IF THAT WAS A PEER, IT WOULD BE A REAL SOCIAL BENEFIT. HELP COVERING THE NEWER MEDICAL EXPENSES.

IF WE COULD HAVE SOMEONE COME IN AND TAKE CARE OF [] SO THAT THE CAREGIVER CAN GET A BREAK.

MORE FINANCIAL AID.

MORE WEEKEND RESPITE.

IT WOULD BE SUPPORT FOR HER TO ATTEND UPEI. SHE WOULD NEED TRANSPORTATION, AND A WORKER TO GO WITH HER.

MORE MONEY WOULD BE GOOD SO WE COULD GO OUT AND DO MORE FUN THINGS WITH []

A LITTLE MORE MONEY FOR HIM.

MORE ONE TO ONE SUPPORT.

WE DO NOT HAVE TRANSPORTATION, WE WALK. I WISH THEY WOULD HAVE A BUS OR A VAN, THAT THEY COULD PICK [] UP AND GO AND DO DIFFERENT THINGS LIKE GO TO RAINBOW VALLEY, STUFF LIKE THAT.

MORE FUNDING FOR DIFFERENT THINGS TO HELP HER SOCIALLY. I AM THE ONLY ONE THAT WORKS SO IT IS IMPOSSIBLE FOR ME TO TRY TO GET HER OUT TO INTERACT WITH OTHER KIDS AND FINANCIALLY IT IS ALMOST IMPOSSIBLE TO GET HER INTO DIFFERENT THINGS THAT SHE WOULD ENJOY.

MORE FINANCIAL AID FOR EQUIPMENT FOR HOME RENOVATIONS FOR []

I THINK [] LIFE IS PRETTY HAPPY. HE HAS A LOT OF SUPPORT AND PEOPLE IN HIS LIFE WHO LOVE HIM. THE ONLY THINK WOULD BE CERTAIN EXPENSES FOR EXAMPLE [] NEEDS HIS TEETH DONE WHICH WILL COST ABOUT \$1000.00 SO THAT WOULD BE THE ONLY THING, DIFFERENT EXPENSES LIKE THAT. I KNOW THAT OTHER PEOPLE HAVE RECEIVED BENEFITS FOR THEIR TEETH SO THERE ARE TWO SETS OF RULES IT SEEMS.

I THINK TO PARTICIPATE IN MORE THINGS ON THE ISLAND, LIKE MAYBE GO TO A CONCERT OR TWO, AND A SUPPORT SERVICE THAT COULD HELP ACCOMPANY HIM HOWEVER WITH KIDS IN THE AGE APPROPRIATE TO HIM.

SOME HELP WITH CLEANING AROUND THE HOUSE.

I THINK MORE HOURS WITH HIS WORKERS, MAYBE MORE MONEY, SO WE COULD DO MORE FUN THINGS AND GET OUT OF THE HOUSE MORE.

REINSTATEMENT TO DSP, SO THAT SHE HAS THE \$50-60 A MONTH FOR SOCIAL THINGS THAT SHE NEEDS. AND ONE ON ONE PERSON THAT WOULD COME IN TO TAKE HER BOWLING, AND RESTAURANTS. SHE HAS NO FAMILY IN PEI SO SHE GOES NO WHERE NOW.

MORE FINANCIAL SUPPORT.

FINANCIAL SUPPORT FOR SPEECH THERAPY.

HE GOES OUT TWICE A WEEK, BUT WE CANNOT GET HIM TO STAY FOR ANY LENGTH OF TIME WHEN HE DOES GO. I WOULD LIKE TO SEE HIM GO OUT FOR LONGER HOURS, AND IT DOES MAKE IT HARD BECAUSE I DO NOT GET TO GO MUCH, AND IT IS HARD TO FIND SOMEONE TO WATCH [] THAT CAN HANDLE HIM.

ONE ON ONE SUPPORT

ACCESS TO MORE PHYSIOTHERAPY AND OTHER THINGS THAT, LIKE WHEN WE NEEDED A NEW WHEELCHAIR, IT TAKES SO LONG TO GET AN APPOINTMENT. IT TAKES SO LONG TO GET ANYTHING TO GET DONE THROUGH THE GOVERNMENT.

PAID EMPLOYMENT

MORE MONEY FOR MORE SUPERVISION REASONS.

MORE TIME AT HOME WITH HER MOTHER.

PROBABLY MORE MONEY TO ACCESS A JOB(LIKE TO PHYSICALLY GET THERE).

I DO NOT THINK THERE WOULD BE ANYTHING.

MORE MONEY. WHEN YOU CONSIDER THAT THERE IS TWO OF US LOOKING AFTER HIM FOR 24 HOURS, IT IS NOT MUCH MONEY, THAT WORKS OUT TO \$2.59.

LITTLE BIT MORE HELP ON OUR TRAVEL EXPENSES TO HALIFAX WHERE SHE HAS TO BE TREATED.

I WOULD SAY SOME ONE-ONE-ONE TIME, SOMEONE TO TAKE HER OUT. AS A CAREGIVER OF 6 PEOPLE, I CANNOT DO EVERYTHING FOR THEM THAT I WOULD LIKE TO DO, LIKE SPECIAL OUTINGS AND THINGS LIKE THAT.

A CONSULTANT TO RUN HER ABA PROGRAM.

MONEY FOR DRUGS. UNLESS THE DOCTORS TAKE THEM AWAY.

I CANNOT THINK OF ANYTHING. SHE CANNOT COMMUNICATE. SHE GOES TO GLENCLIFFA CAMP ONCE A MONTH, WHERE SHE SEES HER FRIENDS, AND SHE REALLY LOOKS FORWARD TO THAT. IN ONTARIO, WE TOOK HER TO RIDING STABLES, AND SHE REALLY ENJOYED THAT.

MORE ACTIVITIES GEARED TOWARDS PEOPLE IN WHEELCHAIRS.

HAVE A CAREGIVER TO TAKE HIM OUT TO SOCIAL EVENTS.

PAID WORKER TO TAKE HIM OUT IN THE AFTERNOONS AND EVENINGS. TO DO SOCIAL THINGS, TRUCK SHOWS, THE MALLS, ETC.

[] WAS ABLE TO STAND WHEN HE WAS GETTING PHYSIOTHERAPY AND THE DOCTOR SAID IF HE HAD SOMEONE TO ENCOURAGE HIM TO EXERCISE MORE HE MIGHT BE ABLE TO WALK. HE WILL NOT DO IT FOR MY WIFE OR ME BUT I THINK HE WOULD IF A THIRD PERSON PUSHED HIM MORE.

THERE NEEDS TO BE AN EPILEPTIC SOCIETY/ORGANIZATION TO HELP TAKE CARE LIKE TRANSPORTATION AND HELPING WITH GETTING [] A JOB AND VOCATIONAL TRAINING, TUTORING WITH SCHOOL.

MORE FINANCIAL AID.

MONEY FOR GLASSES, THIS IS THE THIRD PAIR SHE BROKE.

MONEY FOR CLOTHING AND PERSONAL THINGS.

MORE PROGRAMS FOR HER.

RESPITE CARE FOR THE CAREGIVER.

ANOTHER HEARING AID.

TRANSPORTATION TO ACTIVITIES OR PROGRAMS.

MONEY FOR CLOTHING AND OUTINGS, MOVIES OR SOMETHING.

Appendix B:

CLIENTS

QUESTION: IF YOU COULD CHANGE ONE BARRIER TO MAKE YOUR LIFE BETTER, WHAT WOULD IT BE?

TO MAKE WALKING EASIER - NO CURBS, BETTER SIDEWALKS, GENERAL ACCESSIBILITY.

TO IMPROVE ACCESSIBILITY AND TO IMPROVE SNOW CONTROL GENERALLY. I ONLY WORK SEASONALLY BECAUSE THAT IS THE ONLY JOB I COULD FIND THAT WAS ACCESSIBLE. I WOULD LIKE TO WORK MORE WEEKS A YEAR, BUT IT IS VERY DIFFICULT GETTING TO WORK.

BE ABLE TO GO BACK TO WORK. WORKED WITH PEI GOVERNMENT, NOW OUT ON SICK LEAVE, BUT ON PRIORITY LIST UNDER THEIR CONTRACT UNTIL JUNE 2005, IF ANYTHING CHANGES HEALTH WISE AND I GET BETTER, THEN IF I AM ABLE TO GO BACK TO WORK I WILL DO THAT.

LOVE TO GO TO THE GYM, TO EXERCISE MY LEGS, BUT I CANNOT AFFORD GAS OR MILEAGE. I AM SICK OF SITTING IN THE HOUSE ALL THE TIME, IT IS PRETTY BORING.

STUDENTS TO COME AND TAKE ME PLACES INTO THE COMMUNITY TO SOCIAL EVENTS.

EMPLOYERS TO HIRE PEOPLE WITH DISABILITIES.

MY HEALTH. I GUESS THAT THAT IS MY ONLY BARRIER. I HAVE TO HIRE PEOPLE TO CUT MY GRASS, AND SHOVEL SNOW FOR ME, BECAUSE SOMETIMES I AM UNABLE TO DO IT MYSELF. SOMETIMES, I AM UNABLE TO WALK UP OR DOWN STAIRS, SO I HAVE TO SLEEP ON THE COUCH DOWNSTAIRS.

SCOOTER, 4 WHEELS TO HELP MOVE AROUND OUTSIDE AND SHOPPING.

NOT ENOUGH INCOME TO GO AROUND, MAKES THINGS VERY STRESSFUL.

LACK OF WHEELCHAIR ACCESSIBLE APARTMENTS & OTHER BUILDINGS, LIKE MY DENTIST, I WOULD LIKE TO SEE THAT CHANGED.

MY OWN TRANSPORTATION, I CAN DRIVE.

THE ABILITY TO VOLUNTEER OR ATTEND SOCIAL PROGRAMS. I LIKE TO KEEP MY MIND ACTIVE WHILE I AM RECOVERING FROM MY STROKE SO I DO NOT GET DEPRESSED.

MORE WHEELCHAIR ACCESSIBILITY, MORE RAMPS TO GET IN TO PLACES, MORE DISABILITY PARKING SPACES THAT DO NOT HAVE CURBS TO NEGOTIATE.

ABLE TO DRIVE, FIND RELIABLE TRANSPORTATION.

A BATHROOM DOWNSTAIRS WITH A SHOWER THAT IS WHEELCHAIR ACCESSIBLE, I DESPERATELY NEED A PLACE I CAN TAKE A SHOWER.

ABLE-BODIED PEOPLE HAVE TO THINK MORE ABOUT PEOPLE WHO ARE IN WHEELCHAIRS, THEY DO NOT KNOW WHAT IT IS LIKE.

I WOULD LIKE TO MOVE CLOSER TO TOWN, SO IT IS MORE ACCESSIBLE FOR ME TO DO THINGS I LIKE, SOMETIMES IT IS BORING.

DIFFERENT ACCOMMODATIONS AND HELP TO MOVE TO THEM.

GET A JOB

SOMEONE TO HAVE MEALS BROUGHT IN, AS I AM ONE HANDED AND IT IS HARD TO PREPARE MEALS, AND THERE IS NO MONEY HARDLY TO PAY RENT.

BETTER TRANSPORTATION.

MONEY, NOT ENOUGH MONEY FOR THINGS THAT I NEED, LIKE A NEW COAT.

ELECTRIC WHEELCHAIR WOULD BE NICE.

HELPERS TO HELP WITH THE HEAVY HOUSEWORK.

IF I HAD TRANSPORTATION. I THINK WHEN I GO FOR INTERVIEWS THAT THEY SEEM TO SEE THE CHAIR FIRST. I THINK THERE NEEDS TO BE MORE EDUCATION AND COMPASSION BY EMPLOYERS.

HAVE MY OWN PLACE.

HELP WITH JOINING SPORTS.

I WOULD GET MORE TRANSPORTATION.

ACCESSIBLE PLACES TO GO, WHEELCHAIR ACCESSIBILITY.

OUTSIDE DECK - MAKE IT BIGGER FOR MY SCOOTER TO TURN. GOES FROM WHEELCHAIR TO THE SCOOTER. SCOOTER HELPS ME MOVE AROUND OUTSIDE IN THE SUMMERTIME.

INCOME FROM A FULL TIME JOB.

PAID CAREGIVER TO TAKE ME TO SOCIAL THINGS.

I WOULD REMOVE THE LITTLE LIP ON THE FRONT DOOR.

BE ABLE TO GO TO WORK.

HOW PEOPLE PERCEIVE ME IN SOCIETY, LOOK AT ME FOR MY ABILITIES RATHER THAN MY DISABILITIES.

ALL ONE LEVEL IN MY HOUSE.

MORE ACCESSIBILITY TO PUBLIC PLACES AND TO GET IN AND OUT OF VEHICLES, I HAVE TO USE A TRANSFER BOARD AND IT IS VERY TIRESOME FOR ME.

ACCESSIBILITY - ACCESSIBLE PUBLIC HOUSING, FIND EMPLOYERS WILLING TO WORK WITH YOUR DISABILITY, ACCESSIBILITY TO PUBLIC PLACES.

IT IS DIFFICULT TO GET TO DOCTORS AND OTHER PLACES BECAUSE MY HUSBAND IS WORKING AND I DO NOT HAVE TRANSPORTATION.

SOMEBODY TO BE A FRIEND WITH AND DRIVE ME AROUND IN THE WINTER TIME SO I WILL NOT BE SO LIMITED IN THE WINTER TIME.

MOBILITY

PEOPLE TO HIRE YOU WHEN YOU HAVE A DISABILITY. I WANT TO WORK BUT IT IS HARD TO WORK BECAUSE NO ONE WILL HIRE ME.

UPDATE MY EDUCATION SO I CAN GET A DESK JOB, OFFICE JOB RATHER THAN WORK IN A FISH PLANT LIKE I DO NOW.

BED, PNEUMATIC ONE SO IT CAN HELP ME GET OUT OF BED.

TAKE SOME KIND OF WORK AT HOME, CALLING ON THE PHONE OR SOMETHING LIKE THAT.

PROXIES

QUESTION: IF YOU COULD CHANGE ONE BARRIER TO MAKE YOUR LIFE BETTER, WHAT WOULD IT BE?

COMMUNICATION PROBLEMS WITH FRIENDS & FAMILY & OTHERS.

HIS POOR HEALTH.

LIFE SKILLS/JOB SKILLS COACHING ARE LIMITED.

HER MAJOR PROBLEM IS WITH COMPREHENSION.

GETTING [] SOME SPEECH THERAPY.

IT COMES DOWN TO A VEHICLE AGAIN. IT IS DIFFICULT TO ALLOW HER TO GO PLACES OR ATTEND ACTIVITIES WITHOUT TRANSPORTATION. WE LIVE IN CORNWALL AND SO GETTING TO TOWN IS NOT THAT EASY.

COMMUNICATION, FINDING SOMEONE TO WORK WITH HIM, SPEECH THERAPY AND SOCIAL SKILLS.

I WOULD HAVE TO SAY THE PEOPLES ATTITUDE TOWARDS HER DISABILITY. I GUESS IF THERE WAS MORE AWARENESS OF THE ILLNESS.

FOR ONE THING, I WOULD LIKE HIM TO EAT LESS. IF HE HAD BETTER SPEECH IT WOULD MAKE LIFE EASIER FOR HIM.

IF THERE WAS MORE ONE ON ONE, SHE COULD PROBABLY DO MORE THINGS OUTSIDE OF THE HOUSE.

CHANGE OF ATTITUDE OF PEOPLE IN THE COMMUNITY AND IN GENERAL BECAUSE THERE IS LOTS OF PEOPLE THAT DO NOT REALLY UNDERSTAND INTELLECTUAL DISABILITIES.

HELP WITH HER EYESIGHT PROBLEMS.

THE ABILITY TO KNOW THE VALUE AND HOW TO COUNT MONEY.

THAT HE COULD TALK AND COMMUNICATE WITH US.

OPPORTUNITY TO HAVE PAID STAFF FOR RECREATIONAL ACTIVITIES AND PAID TRANSPORTATION COSTS FOR THAT AS WELL. TO ENABLE HIM TO HAVE MORE THAN ONE OUTING A MONTH THAT IS PAID FOR BY DSP, IT IS TOO LIMITED.

AN ELECTRIC WHEELCHAIR.

HELP WITH HER FOOT PROBLEMS.

IF SHE COULD GO OUT MORE, IF SHE HAD SOMEONE ELSE, THE GIRL THAT TAKES HER OUT DOES AS MUCH AS SHE CAN, BUT SHE HAS ANOTHER JOB AS WELL, SO SHE CANNOT TAKE HER OUT MORE THAN ONCE OR TWICE A WEEK. THAT HAS MADE A WORLD OF DIFFERENCE FOR [], I WISH THAT WE HAD ANOTHER GIRL THAT COULD TAKE HER OUT A FEW TIMES A WEEK TOO.

THERE IS NOTHING THAT COMES TO MIND.

THAT HE COULD GET SOME HELP AND SUPPORT TO READ BETTER.

THE PROPER HELP WITH DEALING WITH THE DISABILITY AND MAKING SURE HE GETS THE PROPER HELP THAT HE NEEDS.

QUALIFIED MALE WORKERS THAT ARE TRAINED & CONSISTENT, UNSUPERVISED RESPITE WORKERS THAT ARE ACCOUNTABLE. THERE JUST ARE NOT ANY. IT AS A CRITICAL CONDITION, THE LACK OF THESE PEOPLE.

MORE LANGUAGE SKILLS AND MORE SOCIAL GROUPS.

HIS HEALTH BACK, BUT I CANNOT DO THAT.

HELP WITH REDUCING AND ELIMINATING [] ANGER.

HELP WITH [] PHOBIAS AND FEARS.

ACCESSIBILITY INTO PUBLIC PLACES, MANY ARE NOT.

I MENTIONED THE AIR CONDITIONER, THAT IS THE BARRIER WE ARE TRYING TO GET OVER NOW, A PORTABLE AIR CONDITIONER IS WHAT WE ARE LOOKING FOR.

BETTER HEALTHCARE ON PEI.

SHE DOES NOT HAVE THE USE OF HER HANDS SO I GUESS I WOULD WANT THAT BACK.

MORE SUPPORT IN SCHOOL.

HAVE KIDS UNDERSTAND MORE ABOUT HEARING IMPAIRS. MORE AWARENESS OF IT ALL. I HAVE ALWAYS TAUGHT THEM IT IS NO DIFFERENT THAN WEARING GLASSES BUT OTHER CHILDREN DO NOT THINK THAT WAY.

IF SHE COULD LEARN TO DO CHORES AROUND THE HOUSE. THAT WAY SHE COULD LOOK AFTER HERSELF.

I WOULD LIKE TO HAVE SOME OF HER BROTHERS AND SISTERS TO HAVE MORE CONTACT WITH HER.

IT WOULD BE NICE IF HE COULD WORK WITH JUST ONE PERSON, BUT HE NEEDS IT TO BE ONE ON ONE

ALONE AND BORED TOO MUCH WITH NOTHING TO DO, NEEDS MORE PAID PROGRAMS OR ACTIVITIES, OR CAREGIVER TO TAKE HER PLACES AND DO THINGS WITH, AND TO TEACH HER JOB AND LIFE SKILLS.

I THINK HIS LOW SELF-ESTEEM HAS A LOT TO DO WITH THINGS, NOT HAVING ANY MOTIVATION TO DO THINGS. THERE IS NO SERVICE OR EQUIPMENT BARRIERS THAT I CAN THINK OF THAT CAUSE PROBLEMS.

SHE IS HAPPY AND NEVER COMPLAINS, AND HER HEALTH IS PRETTY GOOD, SO I DO NOT SEE ANYTHING AT THE PRESENT TIME. I LIKE THE WAY SHE IS GETTING ALONG WITH EVERYTHING, AND A COUPLE OF GIRLS PICKS HER TWO NIGHTS A WEEK TO DO SOMETHING SO I THINK THAT SHE IS DOING WELL.

HER STRESS LEVEL. SHE VERY UNCOMFORTABLE IN NEW SITUATIONS. SHE FINDS IT HARD TO DO SOMETHING DIFFERENT.

SHE SUFFERS WITH A MENTAL ILLNESS AND IT SEEMS TO BREAK DOWN WHEN SHE STARTS TO GET IT TOGETHER. IF SHE COULD BE EMOTIONALLY WELL THEN WE COULD GET HER PAST THAT BARRIER ONTO NEW THINGS.

IT WOULD BE HIS STRESS LEVEL. HE HAS PROBLEMS WITH HIS MEMORY WHEN HE GETS WORKED UP.

SUPPORT WHEN SHE WOULD BE WORKING. SHE WOULD NEED EMOTIONAL SUPPORT SO AS NOT TO GET CONFUSED AND UPSET.

JUST GETTING HELP GETTING HIM TO RELAX.

MORE TRANSPORTATION.

PROVIDE HIM WITH FINANCIAL SUPPORT FOR ACTIVITIES.

ONE TO ONE SUPPORT, PAID, TO HELP HIM OUT IN SCHOOL, SO HE CAN LEARN TO READ BETTER.

SHE IS NOT DOING BAD RIGHT NOW, SHE ENJOYS GOING TO WORK. I CANNOT THINK OF ANYTHING OFF HAND.

JUST THAT THERE WERE MORE JOBS AVAILABLE FOR PEOPLE WITH HIS MENTAL CAPACITY.

FOR EMPLOYERS TO UNDERSTAND THAT BEING DISABLED DOES NOT MEAN INCAPABLE! HE HAD TRAINED AT [] AND THEY KNEW HIS CAPABILITIES, HIS IS POLITE AND RESPECTFUL. A JOB WAS PROMISED TO HIM, BUT THE SUPERVISOR HE WAS TRAINING WITH WENT AWAY ON VACATION AND THE JOB HE WAS TRAINING FOR JUST DISAPPEARED! HE WAS ASSURED THE JOB, BUT HE DID NOT GET IT BECAUSE HE WAS DISCRIMINATED AGAINST BECAUSE OF HIS DISABILITIES, BUT I CANNOT PROVE IT.

I WOULD LIKE TO GET RID OF THE BODY PROCESSOR HE HAS AND GO TO AN EAR LEVEL.

I WOULD GET HIM A FULL TIME TEACHERS ASSISTANT THAT IS TRAINED IN AUTISM. HE IS NOT GETTING ENOUGH ONE ON ONE TEACHERS ASSISTANT TIME. HE IS SO HIGH FUNCTIONING THAT HE SEEMS TO BE LOST IN THE SYSTEM AND IT IS FORGOTTEN THAT HE HAS A DISABILITY.

HIS DESTRUCTIVE BEHAVIOR, IF HE COULD TONE IT DOWN, IT WOULD HELP HIM BE MORE ACCEPTABLE IN PUBLIC.

MORE PROFESSIONAL PHYSICAL THERAPY OR OCCUPATIONAL THERAPY OR SPEECH THERAPY.

HE WOULD LIKE TO HAVE A LITTLE JOB OF HIS OWN. IT WOULD MAKE HIM FEEL BETTER ABOUT HIMSELF.

HAVE SOMEBODY WHO COULD PICK HER UP, SO SHE COULD HAVE MORE OPPORTUNITY TO GO OUT AND GO PLACES, AND RIGHT NOW I CAN'T DO THAT, BECAUSE I'M TAKING CARE OF MY HUSBAND.

PROBABLY HER PHYSICAL LIMITATIONS THAT PREVENT HER MOBILITY.

MORE ACCESS TO SOCIAL ACTIVITIES.

I THINK THE BIGGEST BARRIER HE HAS IS THAT HE CANNOT WALK. IF THERE WAS A WAY THAT HE COULD WALK, OR EVEN BE ABLE TO MOVE AROUND EASIER, IT WOULD BE GREAT.

A PAID CAREGIVER SO HE CAN STAY IN HIS HOME.

I DON'T KNOW...IT'S REALLY DIFFICULT BECAUSE I DON'T HAVE A VEHICLE B/C I AM DISABLED TOO. I WOULD TAKE HIM PLACES IF I COULD.

TRANSPORTATION, HE DOES NOT HAVE ENOUGH OF THAT, IF HE WANTS TO GO SOMEWHERE WE HAVE TO HAVE TO TAKE HIM.

HE NEEDS EXERCISE AND STIMULATION PROGRAM, ONE ON ONE SUPPORT TO RECREATIONAL ACTIVITIES. WE DID HAVE A STUDENT TO DO THAT, IT WAS A FUN THING. HE ENJOYED THAT, FUNDING WAS CUT FOR THAT SO WE LOST THAT BUT WE REALLY NEEDED IT. HE WEIGHS 260 SOME POUNDS AND HE IS ONLY 5 FT TALL NOW BECAUSE HE DOES NOT GET ANY EXERCISE.

MORE ACTIVITIES PLANNED BY DSP.

WHEELCHAIR ACCESSIBLE TRANSPORTATION.

PEOPLES ATTITUDES, IT IS THE MOST HINDRANCE TO HER.

WHERE WE LIVE IN PEI, THE BIGGEST PROBLEM WE HAVE IS ACCESS TO SPEECH AND READING PROGRAMS WE NEED.

I WOULD GIVE HIM MORE SPEECH THERAPY.

MAKING THE HOUSE ACCESSIBLE TO HIM.

SHE HAS A GREAT WISH TO BE WORKING. THAT IS WHAT SHE WANTS, AND AS A PARENT IT IS VERY DIFFICULT TO GET IN TOUCH WITH A MENTOR FOR EMPLOYMENT BECAUSE SHE IS NOT RECEIVING ANYTHING FROM THE GOVERNMENT.

MORE SOCIALIZATION WITHIN THE COMMUNITY.

PEOPLES AWARENESS OF HIS DISABILITY.

I WOULD TAKE AWAY HIS BLINDNESS.

MORE ONE ON ONE SUPPORT FOR EDUCATIONAL AND SOCIAL DEVELOPMENT.

IT WOULD BE LOVELY IF MORE PEOPLE WOULD OFFER TO TAKE HIM OUT MORE, I HAVE A HUSBAND AND A FAMILY AND I CANNOT ALWAYS GO WHERE HE WANTS TO GO.

MORE HELP AT SCHOOL, TEACHERS AIDS, ONE-ON-ONE SUPPORT.

TRANSPORTATION IS A BIG FACTOR. I WOULD LIKE TO SEE MORE TRANSPORTATION AVAILABLE.

GETTING THE SPLINT WOULD MAKE HER LIFE BETTER.

SOMEONE COMING TO DO THINGS WITH HIM, LIKE A BIG BROTHER.

I THINK THAT SOMETHING THAT WOULD MAKE HER LIFE BETTER WOULD BE SOME TRANSPORTATION SERVICES.

I DO NOT THINK THERE IS ANYTHING THAT COULD MAKE IT ANY BETTER.

I SUPPOSE IF THERE WAS MORE TRANSPORTATION AVAILABLE FOR DISABLED PEOPLE.

WELL, IT WOULD BE WONDERFUL IF SHE COULD WALK , BUT SHE

SHE COULD GO TO SCHOOL AND LEARN TO READ AND WRITE.

I WOULD TEACH HIM HOW TO LIVE ALONE. HE IS AFRAID TO TRY AND DO THAT.

EDUCATE EMPLOYEES TO PEOPLE WITH DISABILITIES.

HIS SPEECH BARRIER - IF HE COULD TALK MORE CLEARLY, IT WOULD BE SO MUCH EASIER FOR HIM.

I DO NOT THINK THERE IS ANYTHING THAT COULD MAKE IT EASIER.

I DO NOT THINK THERE WOULD BE ANYTHING, HE SEEMS VERY HAPPY WITH HIS LIFE.

LANDSCAPING AT THE SCHOOL. THE LANDSCAPING IS HORRENDOUS AND IT IS HARD FOR HER TO GET AROUND IN HER WHEELCHAIR.

FOR HIM TO BE ABLE TO HAVE A ONE ON ONE WORKER.

LACK OF STAFF TO TAKE HIM PLACES.

MORE ACTIVITIES OUTSIDE THE HOUSE - THE LACK OF A SOCIAL LIFE COMPOUNDED BY LACK OF TRANSPORTATION AND SOMEONE TO GO WITH HIM.

HELP WITH TRANSPORTATION SERVICES.

IF I HAD SOMEONE TO GO WITH HER TO PLACES AND STUFF LIKE THAT , SHE WOULD BE A LOT HAPPIER.

I WOULD PROBABLY TAKE AWAY THE OPINIONS AND ATTITUDES. I DO NOT TREAT HIM ANY DIFFERENTLY THAN MY OLDER SON, AND I WANT HIM TO THINK THAT HE IS NOT SPECIAL ABOVE OR BEYOND ANY OTHER CHILD.

REDUCE HIS COMMUNICATIONAL BARRIER BECAUSE IF HE COULD TALK WE COULD UNDERSTAND HIM MORE. BUT I HOPE THAT THAT WOULD COME WITH TIME AND THERAPY. HE IS LEARNING.

IF THERE WERE MORE FINANCIAL SUPPORT SO HIS MOTHER COULD STAY HOME AND LOOK AFTER HIM AND POSSIBLY SOME RESPITE CARE AS WELL.

TO BE ABLE TO GO TO SOME SOCIAL ACTIVITIES DURING THE EVENINGS.

HELP WITH HIS MOBILITY.

TO BE ABLE TO GET OUTSIDE MORE AND BE AROUND PEOPLE.

MAKING SURE THAT MORE PLACES ARE WHEELCHAIR ACCESSABLE SO THAT [] CAN LOOK FOR A JOB AND GET A JOB.

OUTSIDE OF THE COMMUNITY THE ACCEPTANCE LEVELS ARE NOT AS HIGH BECAUSE HIS DISABILITY IS NOT AS RECOGNIZED.

IF I COULD ELIMINATE HIS FEEDING TUBE.

SOME ACTIVITIES THAT [] WOULD LIKE AND BE ABLE TO PARTICIPATE IN.

HIS OWN TV IN HIS ROOM WITH A DISH.

I WOULD LIKE TO HAVE MORE MONEY SO I CAN TAKE HIM OUT TO MORE PLACES, BECAUSE EVERYTHING THAT IS GOING ON IS HARD ON HIM. TO DO ANYTHING COSTS MONEY AND WHEN YOU ARE JUST GETTING BY IT IS EXTREMELY DIFFICULT.

[] IS NEVER HAPPY BECAUSE SHE IS NOT HAPPY WITH HERSELF. SHE GETS FRUSTRATED VERY EASILY AND I TELL HER DO NOT GET MAD FOR NOTHING. SHE HAS FOUGHT ALL HER LIFE WITH HER PARENTS, BROTHERS AND SISTERS. SINCE SHE HAS COME HERE, SHE HAS BEEN GETTING BETTER, BUT THERE IS ROOM FOR A LOT MORE IMPROVEMENT.

IF I COULD CHANGE ONE BARRIER TO MAKE []'S LIFE BETTER, IT WOULD BE TO HELP CHANGE THE PRECONCEPTIONS OF PEOPLE WITH DISABILITIES.

SHE IS A FAIRLY BIG GIRL, SO HER WEIGHT HAS BECOME SORT OF A BARRIER.

TO EDUCATE PEOPLE ABOUT DISABILITIES AND DISABLED PEOPLE.

I WOULD ELIMINATE HER HEARING LOSS, THAT IS ABOUT ALL I CAN THINK OF.

HELP WITH TRANSPORTATION SERVICES.

SOCIALLY OR WHAT DO YOU MEAN, THAT IS A VERY BROAD QUESTION.. I DO NOT KNOW HOW TO ANSWER THAT, YOU CANNOT CHANGE A DISABILITY. SOME PEOPLE MIGHT SAY, GOVERNMENT. THE GOVERNMENT SHOULD DO MORE, BUT WE HAVE NEVER HAD ANY PROBLEMS, AND THE SUPPORTS THAT THE GOVERNMENTS HAVE GIVEN US WE ARE 100% SATISFIED WITH. I HAVE NEVER BEEN UNSATISFIED WITH A GOVERNMENT SERVICE. I CANNOT COMPLAIN, WE HAVE NEVER BEEN REFUSED ANYTHING WE HAVE ASKED FOR, BUT HAVE NEVER ASKED FOR ANYTHING OUTRAGEOUS.

I DO NOT KNOW, SHE IS HAPPY NOW, AND THAT IS ALL THAT MATTERS.

LACK OF FRIENDS.

TO HAVE SOMEONE WITH HIM CONSTANTLY, BESIDES US, TO TAKE HIM OUT OF THE HOME.

I WISH THAT PEOPLE, LIKE BIG BUDDY WOULD STAY IN HER LIFE, THEY COME, THEN THEY ARE GONE...

IF HE COULD REDUCE HIS WEIGHT.

TO HAVE SOMEONE STAY OVERNIGHT IN THE WINTERS.

TO HAVE HIS CARE WORKER OVER NIGHT.

A BETTER AWARENESS TO THE PUBLIC OF CHILDREN WITH AUTISM BECAUSE WHEN WE GO TO THE DOCTORS OFFICE, AND SOMETIMES THE WAY [] MAY BE ACTING WITH TOYS AND THINGS IS DISTURBING TO SOME PEOPLE AND A LOT OF MISCONCEPTIONS ARE BROUGHT ONTO THE DISEASE BECAUSE OF IT.

THERE IS NOT MUCH IN THE LINE OF ACTIVITIES. THERE IS NOT A WHOLE LOT UP HERE, NO WHERE FOR HIM TO GO AND DO THINGS.

GET TRANSPORTATION FOR HER TO GO PLACES.

JUST MORE FINANCIAL SUPPORT FOR HIS THERAPY HOURS.

MORE FINANCIAL AID.

I GUESS IT WOULD JUST BE HER MENTAL HEALTH, IF IT WAS BETTER HER LIFE WOULD PROBABLY BE BETTER AS WELL.

I WOULD WANT TO TAKE AWAY HIS BAD TEMPER BECAUSE HE LOSES IT TOO EASY AND GETS REALLY CROSS.

THAT HE COULD GET OUT OF THE HOUSE EASIER.

I DO NOT KNOW UNLESS SHE DIED AND WENT TO HEAVEN, SHE HAS GOT IT PRETTY GOOD.

REMOVE HER NEIGHBOURS. THAT IS THE ONLY THING I CAN THINK OF. THEY ARE THE ONLY PROBLEM THAT SHE HAS,

THEY ARE TRYING TO GET [] IT'S NOT EVEN HERS, IT BELONGS TO THE GOVERNMENT. THEY JUST DO NOT TREAT HER VERY WELL.

IF SHE COULD TALK THAT WOULD BE GREAT, MAYBE A DEVICE THAT COULD HELP HER COMMUNICATE WOULD BE GREAT.

I WISH SHE WAS CAPABLE OF WORKING, AND SHE GETS MIXED UP WITH MONEY SOMETIMES. BUT SHE IS PRETTY GOOD, SHE IS BETTER NOW THAN SHE EVER WAS.

I WOULD ELIMINATE THE VIOLENT BEHAVIOURS.

I WOULD LIKE TO BE ABLE TO SPEND MORE TIME WITH HER, BUT I WORK, SO IT IS HARD. I THINK IT WOULD BE GREAT FOR HER IF I COULD STAY HOME WITH HER.

MORE INDEPENDENCE, ONE ON ONE SUPPORT IS NEEDED.

IF I COULD IMPROVE HER COMMUNICATION SKILLS.

FUNDS FOR PROPER ACCOMMODATIONS.

I JUST WISH THAT HE HAD HIS EYESIGHT.

I WOULD SAY SOCIETY ACCEPTING PEOPLE WITH DISABILITY, FOR PAY TO BE THE SAME WAGE AS YOU OR I WOULD GET.

IT WOULD BE FOR HIM TO HAVE MEANINGFUL EMPLOYMENT, THAT WOULD GIVE HIM MORE INDEPENDENCE, AND HE NEEDS THAT. IT WOULD ALSO GIVES HIM HIS OWN MONEY, AND HELPS HIM FEEL LIKE HE IS DOING SOMETHING USEFUL.

SPEECH THERAPY

THE ABILITY TO GO WHERE HE WANTS WHEN HE WANTS, BECAUSE HIS BIGGEST PROBLEM IS BOREDOM.

MAYBE IF HE HAD A CHAIR THAT HE COULD SIT IN, WITH WHEELS, SINCE HE HAS GAINED WEIGHT, IT IS HARD TO MOVE HIM.

MAKING SURE THERE IS ALWAYS SOMEONE WITH [].

NOT BE ON SO MUCH MEDICATION.

ACCESS TO AN AUTISM CO-ORDINATOR.

THE ISOLATION- HE NEEDS MORE SOCIALIZATION . THERE ARE A LOT OF PROBLEMS WITH THE PROGRAM. "HERE IS THE SERVICES- DEAL WITH IT" I DID NOT THINK THAT IT WAS GOING TO BE LIKE THAT- I THOUGHT THAT IT FOCUSED ON THE NEEDS OF THE PERSON WITH THE DISABILITY. I DO NOT FEEL THAT THIS SURVEY COVERED THE IMPORTANT QUESTIONS.

WELL I GUESS IT WOULD BE ELIMINATE SOME OF HIS BEHAVIOURS.

ONE OF HIS PROBLEM BEHAVIOUR TO BE GONE. BEHAVIOURAL SUPPORT WORKING WITH HIM.

GETTING PEOPLE TO UNDERSTAND, AND TO LISTEN TO WHAT YOU ARE SAYING.

I THINK IT WOULD BE GOOD IF THERE WAS A PROGRAM HE COULD BE IN THAT WOULD GIVE HIM MORE OPPORTUNITY TO BE SOCIAL.

MORE RESPITE CARE.

GETTING SOME HELP WITH GETTING [] TO CONCENTRATE BETTER.

IF WE COULD GET HER WALKING AND STOP THE SEIZURES.

HELP WITH GETTING IN AND OUT OF THE HOUSE.

ACCESSIBILITY & MOBILITY - LIFT FOR VAN, RAMP TO THE HOUSE, QUALIFIED CAREGIVER TO ACCOMPANY HIM TO PLACES HE HAS TO GO.

I WOULD LIKE THE DSP TO BE A UNIVERSAL PROGRAM WHERE EVERYBODY IS GETTING SUPPORT ON A NEEDS BASIS, SPECIFICALLY LOOKING INTO HOUSING WITH RELATIVES OR PARENTS AND THEIR SUPPORT.

HOURS OF WORK - 8 HOUR DAY IS TOO LONG, EMPLOYERS FLEXIBILITY FOR PEOPLE WITH DISABILITIES, THESE PEOPLE NEED MEDICAL APPOINTMENTS, ETC.

MORE ONE TO ONE SUPPORT.

MORE ONE ON ONE.

I WOULD LIVE IN A MORE CENTRALIZED AREA SO THAT [] WOULD HAVE MORE ACCESS TO SOCIAL GROUPS, ACTIVITIES AND PEERS.

SOME HELP FOR [] WITH BEING ABLE TO SPEAK UP FOR HIMSELF AND BE ABLE TO SAY "NO" TO PEOPLE WHEN HE WANTS.

GIVE HER MORE CONFIDENCE IN HER SELF SO SHE COULD DO MORE. SHE DOES NOT LIKE TO GO OUTSIDE WITHOUT ME.

ACCESS TO MORE SUPPORT STUFF - DANCES, PARTIES, SOCIAL THINGS.

IT IS ALMOST IMPOSSIBLE TO ANSWER. THE BARRIER IS EDUCATION - SHE HAS ONLY GRADE 5.

HAVE THINGS TO AMUSE HER AROUND THE YARD SO THAT SHE DOES NOT GET BORED.

HAVE MORE THINGS FOR [] TO DO OUTDOORS FOR ACTIVITIES AND FOR EXERCISE.

LACK OF PUBLIC AWARENESS OF WHAT THE DISORDER CONSISTS OF AND FOR HER TO BE ALLOWED TO BE PART OF THE COMMUNITY AND NOT TO BE SO ISOLATED.

TRANSPORTATION AVAILABLE WHEN WE NEED IT, SOMETHING THAT IS WHEELCHAIR ACCESSIBLE FOR HER TO GET IN AND OUT OF THE VEHICLE.

TUTOR TO TEACH HER TO READ. SHE WAS LEARNING TO READ EARLY ON IN SCHOOL, BUT THEN SHE GOT STUCK WITH STUDENTS TO TEACH HER AND SHE GOT CONFUSED. SHE NEEDS A FRIEND BESIDES ME, TO TAKE HER BOWLING, OR TO READ.

FULL TIME WORK.

SOMETHING TO REDUCE HER SPEECH IMPEDIMENT, I CAN MAKE HER OUT QUITE WELL, BUT IT WOULD HELP HER IN SOCIAL CONTACTS IF SHE COULD SPEAK MORE CLEARLY.

I THINK HER BIGGEST BARRIER IS HER SPEECH IMPEDIMENT.

SHE IS EXTREMELY OVERWEIGHT, BUT IT IS DIFFICULT FOR HER TO DIET WHEN SHE WORKS IN A FAST FOOD RESTAURANT. I NEED SOMEONE TO TAKE HER TO THE GYM, I AM WORKING ON THAT THROUGH COMMUNITY CONNECTIONS.

HER SPEECH, [] SPEECH IS THE WORST OF ALL OF THE 5 GIRLS WHO LIVE WITH ME. SHE CAN SAY [] OR [] BUT MOSTLY SHE HAS TO ACT OUT WHAT SHE IS TRYING TO SAY.

HER INABILITY TO WALK FAR WITHOUT PAIN IS A BARRIER AND I WOULD LIKE HER TO GET BETTER QUALITY FOOTWEAR TO SUPPORT HER FEET.

THE FINANCIAL BURDEN, I NEED MORE MONEY FOR THE ONE-TO-ONE SUPPORT.

HIS TOURETTES, HIS SOCIAL SKILLS. IF WE COULD TEACH HIM - MORE ONE ON ONE WITH PEOPLE. HE DOES NOT KNOW HOW TO READ FACIAL EXPRESSIONS. HE WAS NOT BORN KNOWING, WE HAVE TO TEACH HIM. HE HAS NO FRIENDS. I CANNOT TAKE HIM ANYWHERE. WHEN WE WERE SHOPPING ONCE, WE WERE IN THE LINE OF 10 ITEMS OR LESS, HE STARTED COUNTING THE LADY'S ITEMS AHEAD OF US, SHE HAD 13, AND HE COUNTED THEM...ONE...TWO..."HEY YOU HAVE 13 LADY" PEOPLE LOOK AT ME LIKE I CANNOT CONTROL MY KID, BUT HE DOES NOT

KNOW BETTER.

HELP WITH PEOPLES THOUGHTS ABOUT []. [] IS VERY SELF CONSCIOUS ABOUT HOW PEOPLE LOOK AT HIM.

SIMPLE THINGS LIKE TRYING TO GET HIM A COMPUTER, NO ONE INTERVENES FOR ME, THE SUPPORT JUST IS NOT THERE. IF SOMETHING HAPPENS, IT COMES OUT OF YOUR GROCERY MONEY.

SOCIAL EVENTS/PROGRAMS ARE NOT IN THE COMMUNITY FOR HER TO ATTEND, RESPITE CARE FOR FUN ACTIVITIES, NOT ENOUGH MONEY THERE FOR THAT. PARENTS ARE GETTING DISCOURAGED, WE ARE GETTING WORN DOWN.

HER SPEECH, THEY TRIED AN AID BUT THEY SAID THAT SHE WAS TOO OLD TO BE TAUGHT WITH IT OR SOMETHING.

SOCIAL THINGS WOULD BE BETTER, SHE IS SO MUCH BY HERSELF.

MORE FINANCIAL ASSISTANCE SO WE CAN TAKE HER ON A TRIP. THEY TAKE MONEY OFF OF WHAT SHE SHOULD RECEIVE BECAUSE OF WHAT WE MAKE SO THERE NO EXTRA LEFT OVER TO DO THAT STUFF.

I GUESS IT WOULD PROBABLY BE TRANSPORTATION, THERE IS VERY LITTLE TRANSPORTATION AVAILABLE.

ACCESS TO SERVICES THAT HE NEEDS - SPEECH THERAPY AND THINGS LIKE THAT.

HELP WITH [] IN THE WORK FORCE

SPEECH THERAPY OPTIONS SO HE COULD LEARN TO SPEAK BETTER.

THE FEAR THAT PEOPLE WITH DISABILITIES MAY NOT BE ABLE TO DO THE JOB AND WORK AT THE SAME PACE AS OTHER PEOPLE.

MAYBE PAY MORE MONEY SO I COULD GET QUALIFIED PEOPLE TO LOOK AFTER HER. SITTERS DO NOT GO THAT EXTRA MILE FOR HER. I NEED TRAINED PEOPLE TO LOOK AFTER HER THAT WILL TEACH HER DIFFERENT THINGS.

SPEECH PROBLEMS.

THE DSP. I GUESS ONE THING WOULD BE THE LIMIT OF \$2000.00 FOR A LIFETIME OF HOME MODIFICATIONS IS RIDICULOUS. UNLESS THEY CHANGE THAT FIGURE THAN THE CHILDREN ARE GOING TO WIND UP BACK IN THE INSTITUTIONS LIKE THEY USED TO BE. THIS COPAY OF PARENTS IS DISCRIMINATORY BECAUSE MY CHILD WHO IS NORMAL I DO NOT HAVE TO PAY EXTRA, BUT FOR MY CHILD THAT IS DISABLED I HAVE TO CO-PAY UNTIL HE IS 25. I THINK THE OTHER THING IS THAT I CAN GO OVER WHAT THEY ALLOW ON CHILDCARE ALONE AND HE IS ONLY 12 YEARS OLD. THEY HAVE NOT LOOKED AT MEDICAL EXPENSES.

PROPERLY TRAINED SPEECH THERAPIST TO WORK WITH HIM REGULARLY SO HE COULD LEARN TO SPEAK. HE SHOULD HAVE HAD ONE LONG BEFORE NOW. HE IS A 40 YEAR OLD ADULT, BUT THAT WAS NEVER AVAILABLE TO HIM.

THAT [] COULD GET HIS DRIVERS LICENCE.

IF I COULD DO ONE THING, THAT WOULD BE TO TAKE HER FOR MORE DRIVES, SHE LOVES GOING FOR DRIVES.

I WOULD ELIMINATE THE SOCIAL BARRIER SO THAT [] COULD BE MORE SOCIAL AND HAVE MORE FRIENDS.

SELF ESTEEM PROBLEM.

A WAY TO COMMUNICATE WOULD MAKE LIFE BETTER FOR HER.

IF HE COULD READ AND WRITE HE WOULD HAVE IT MADE.

GET MORE MONEY FOR FINANCIAL AID TO PUT [] ON A DIET.

ENOUGH MONEY TO TAKE HER PLACES.

TO SEE HIS BEHAVIORAL MANAGEMENT GET BETTER.

HELP FOR [] TO BE MORE SOCIAL.

TO HAVE HIS FAMILY MORE INVOLVED IN []'S LIFE.

[] IS IN A HARD POSITION, WHEN YOU LOOK AT HIM, YOU THINK THAT HE IS NORMAL, BUT WHEN YOU TALK TO HIM, YOU KNOW HE IS NOT. IT IS HARD FOR HIM TO COMMUNICATE. IT WOULD BE NICE IF HE COULD COMMUNICATE AND EXPRESS HIMSELF, I KNOW THAT IN HIS MIND, HE KNOWS WHAT HE WANTS, BUT JUST CANNOT EXPRESS IT.

A VAN WITH A LOADING RAMP FOR HIS WHEELCHAIR. NOW I HAVE JUST A CAR, I HAVE TO TAKE HIM OUT OF HIS WHEELCHAIR, THEN COLLAPSE THE WHEELCHAIR & PACK IT AWAY. WHEN WE GET TO WHERE WE ARE GOING I HAVE TO DO THE SAME THING. SOMEDAY I HOPE TO HAVE A VAN SO I CAN JUST WHEEL HIM RIGHT ONTO THE RAMP AND INTO THE VAN. HE IS GETTING PRETTY HEAVY.

TELEPHONE DEVICE FOR THE DEAF, HERS IS BROKEN AND THERE IS NO PLACE ON P.E.I. THAT WILL REPAIR IT. COST OF REPAIR AND SHIPPING COST AS MUCH AS BUYING A NEW ONE. SHE IS 15 YEARS OLD, AND WANTED TO GET IN TOUCH WITH ME THE OTHER DAY WHILE I WAS AWAY FROM THE HOUSE. BUT SHE COULD NOT CALL ME.

TRANSPORTATION.

HELP WITH HIS SCHIZOPHRENIA.

MORE EDUCATION - JOB SKILLS.

I WOULD LIKE TO KNOW HOW SHE IS TAKEN CARE OF WHEN I PASS ON.

I WOULD LOVE FOR HIM TO HAVE A BIG BROTHER TRAINED OR FAMILIAR WITH []'S CONDITION. IT WOULD BE GREAT FOR THE BIG BROTHERS/BIG SISTERS TO EXPAND INTO SPECIAL NEEDS CHILDREN.

HELP WITH [] SOCIAL SKILLS

HELP WORKING WITH HIS ATTENTION SPAN

[] SAID HE WOULD HAVE TO HAVE A LABOUR JOB, AND I AM NOT HAPPY WITH THAT. HE IS QUITE CAPABLE OF DOING COMPUTER STUFF, HE IS A TALENTED YOUNG MAN. I WOULD LIKE TO SEE HIM IN A FIELD WITH ADVANCEMENT, LOTS OF PREPARATION FOR CHILDREN WITH DISABILITIES SHOULD BE CHALLENGED AS MUCH AS POSSIBLE, SO THEY CAN BE EDUCATED AND PLACED IN THE WORKFORCE. RATHER THAN BEING BABIED AND BUILDING BIRD HOUSES!

I WOULD LIKE TO REMOVE HER AGGRESSION. THAT IS THE MOST DIFFICULT PART OF HER DISABILITY

BETTER, AND MORE ACCESSIBLE TRANSPORTATION.

TRANSPORTATION PROBABLY WOULD BE THE BIG ONE.

MORE SPEECH THERAPY TO HELP HER SPEECH.

HELPING WITH PEOPLES UNDERSTANDING OF []'S DISABILITY

MORE THERAPY WOULD MAKE []'S LIFE BETTER, AND ADEQUATE PAY FOR THE THERAPIST.

I THINK THAT IF HE COULD WALK ON HIS OWN, IT WOULD BE BETTER FOR HIM. I CANNOT THINK OF ANYTHING ELSE RIGHT NOW.

TO HAVE A RHEUMATOLOGIST ON P.E.I. ESPECIALLY A PEDIATRIC RHEUMATOLOGIST BECAUSE THAT IS WHO SHE SEES AT THE IWK AND IT HAS MADE A WORLD OF DIFFERENCE WITH [].

IF SHE HAD SOME KIND OF GUIDE LINE AROUND THE YARD SO SHE COULD GET AROUND BETTER, MARKERS OR SOMETHING.

MORE FINANCIAL AID.

SOCIETY, THE ATTITUDE OUT THERE. ADDITIONAL COMMENTS ON Q25: WITH A COMPUTER, MY CHILD CANNOT VERBALLY COMMUNICATE. WE WERE DENIED A COMPUTER FOR HIM TO COMMUNICATE WITH (HE HAS BEEN USING ONE TO COMMUNICATE SINCE AGE 8) THEY WENT ON-LINE AND LOOKED AT HIS HOME PAGE AND DECIDED THAT HE COULD VERBALLY COMMUNICATE.

HELP WITH COVERING THE COSTS OF MEDICAL EXPENSES.

IF THINGS COULD BE MORE ACCESSIBLE FOR HER.

WE HAVE GONE IN TO MUSIC STORES TO LOOK FOR WORK, BUT THEY WILL NOT HIRE HIM BECAUSE HE HAS A BAD LIMP AND STAMMERS A BIT IF HE IS NERVOUS. VISIBLE DISABILITIES PREVENT HIM FROM BEING HIRED, THE OPPORTUNITY TO BE EMPLOYED. HE HAS A GREAT KNOWLEDGE OF MUSIC BOTH OLD AND NEW. HE FALLS BETWEEN THE CRACKS BECAUSE HIS DISABILITIES ARE NOT SEVERE.

I WISH HE COULD SPEAK. HE COMMUNICATES THROUGH A LAPTOP, BUT I WISH HE COULD SPEAK FOR HIMSELF.

I THINK IF WE WERE LIVING IN TOWN, IN A MORE POPULATED AREA IT WOULD BE MORE BETTER FOR HIM, BECAUSE HE COULD WALK TO A MALL AND GO LOOK AROUND BY HIMSELF. RIGHT NOW HE DEPENDS ON ME FOR EVERYTHING.

MORE ONE TO ONE SUPPORT.

I WOULD LIKE HIM TO BE ABLE TO GO OUT AND DO FUN THINGS AWAY FROM HOME, WITH SOMEONE OTHER THAN ME, BECAUSE HE IS REALLY ATTACHED TO ME AND HE NEEDS TO BE AROUND OTHER PEOPLE.

FOR PEOPLE TO HAVE MORE AWARENESS TO WHAT AUTISM IS AND HOW IT EFFECTS CHILDREN.

I THINK THE ONLY THING I WOULD SAY WOULD BE TO IMPROVE/FIX HIS TEETH BECAUSE HE IS VERY SELF CONSCIOUS OF THEM.

PROBABLY TO EDUCATE THE PUBLIC THAT HE IS CAPABLE OF DOING SOME WORK, AND THAT IF THEY WOULD GIVE HIM A TRY THAT HE COULD ACCOMPLISH IT.

IT WOULD BE NICE IF THERE WERE MORE WORK IN THIS AREA FOR HIM.

FINANCIAL SUPPORT IS NEEDED, REINSTATE ABILITY FOR HER TO HAVE FUNDS TO SPEND ON SUPERVISED SOCIAL ACTIVITIES, AND/OR ONE ON ONE SUPPORT.

MORE OUTSIDE HELP, PEOPLE TAKING HER SOME PLACE WHEN I COULD NOT.

SOME FINANCIAL ASSISTANCE FOR MY HUSBAND DOING THERAPY WITH [].

HELP WITH SOCIAL SUPPORT.

FIND MORE THINGS TO DO WITH HIS TIME, BECAUSE HE DOES NOT GET INVOLVED WITH A LOT OF STUFF. HE WILL BE SWIMMING THIS SUMMER, I TRY TO KEEP HIM ACTIVE AND AMUSED AND NOT STUCK IN THE HOUSE ALL THE TIME.

I THINK THE THING I WOULD LIKE TO SEE CHANGE THE MOST...THE WAY TEACHERS ASSISTANTS ARE IN SCHOOL OR DAY CAMPS, IT IS REALLY A LOT OF PROCESS AND IT IS STRESSFUL FOR ME, IT SEEMS LIKE EVERYTHING, ONCE YOU GO THROUGH DSP, IT TAKES A LONG TIME. ANYTHING TAKES A LONG TIME TO ACCOMPLISH.

I AM A STRONG BELIEVER IN INCLUSION AND GIVING THEM A CHANCE BECAUSE YOU MIGHT BE SURPRISED AT WHAT THEY CAN ACCOMPLISH.

HIS ABILITY TO THINK IS ON A 5 YEAR OLD, HE IS 33. THERE IS LOTS OF THINGS THAT WOULD BE A BARRIER FOR HIM, SO I DO NOT KNOW ONE IN PARTICULAR.

I DO NOT KNOW, WE ARE REALLY JUST AT THE CHECKUP STAGE.

SHE HAS A LOT OF DISABILITIES, IT WOULD BE HARD FOR ME TO CHOOSE A BARRIER.

MORE THERAPY TO HELP TEACH HER TO NOT DO THINGS THAT ARE NOT SAFE.

TO HAVE HER IN A SPEECH THERAPY CLASS.

HELP WITH GETTING IN AND OUT OF VEHICLES.

ONE-TO-ONE SUPPORT IS NOT THERE. HE NEEDS A CAREGIVER TO TAKE HIM OUT TO SOCIAL ACTIVITIES. ONE TO ONE PAID WORKERS TO ASSIST HIM

THERE IS NOT REALLY TOO MUCH THAT NEEDS TO BE DONE.

FOR [] TO BE ABLE TO STAY NIGHTS, GO CAMPING, DRIVE AND GET HIS EDUCATION

WORKING AND MAKING A LITTLE EXTRA MONEY, THE CLUB HOUSE DID NOT PAY HER SO SHE GOT OUT OF IT.

ACCESSIBILITY TO PUBLIC PLACES AND RESTROOMS. THEY ARE LIMITED EVEN IN STALLS.

MENTALLY HANDICAPPED AND DIABETES. LOOK AFTER HIMSELF.

HEARING AID

CURE HER DISEASE.

AVAILABILITY OF TRANSPORTATION.

OUTGROW HER SEIZURES

Appendix C:

CLIENTS

QUESTION: IS THERE ANYTHING ABOUT THE DISABILITY SUPPORT PROGRAM AND ITS SUPPORTS AND SERVICES THAT YOU WOULD LIKE TO COMMENT ON?

I DO NOT WANT SOMEONE TO TELL ME I CANNOT DO IT BECAUSE OF MY DISABILITY.

I BELIEVE THAT THE SEMINAR THAT I WENT TO THIS WEEK MIGHT HAVE ZEROED IN ON THE DISABILITY/SAFETY A LITTLE MORE.

YOU DO NOT GET ENOUGH MONEY TO LIVE, NO MONEY FOR THE DRUGS THE PROVINCIAL PHARMACY DOES NOT COVER.

IT SHOULD BE BASED ON WHERE THE DEMAND OR NEED IS GREATER, A GREATER DISABILITY, A GREATER DEMAND, THAT IS WHAT THE AMOUNT OF FINANCIAL SUPPORT SHOULD BE BASED ON.

WHEN I GET THAT BIT EXTRA FROM THE DISABILITY SUPPORT PROGRAM IT GIVES ME COURAGE, IT GIVES ME MONEY TO GET OUT AND DO MORE AND HAVE SOME FUN.

IT SHOULD NOT TAKE AS LONG TO GET TECHNICAL EQUIPMENT THAT I NEED, IT TOOK ME A YEAR AND A HALF TO GET A CLOSE CIRCUIT TV THAT I NEEDED. ALSO, THE LEVEL OF MONEY THAT WE GET SHOULD BE RAISED. THERE SHOULD BE A SET AMOUNT INSTEAD OF AVERAGING IT OUT AMONG THE PERSON.

I WISH THEY WOULD ADDRESS THE IMPORTANT THINGS. WE HAVE NO ADVOCACY. THE COUNCIL OF THE DISABLED IS A WRITE-OFF. THERE IS NO ONE BACKING US IF THERE IS A PROBLEM. A PERSON WITH A DISABILITY HAS NO RIGHTS UNDER THE CHARTER. I AM IN COURT RIGHT NOW AND THERE IS NO SUPPORT. THERE IS NO QUALITY OR DIGNITY OF LIFE AND THAT IS CALLED CORRUPTION. THE HUMAN RIGHTS COMMISSION IS TOTALLY CORRUPT.

IT COULD BE IMPROVED IN PARTS. I DO NOT REALLY UNDERSTAND WHAT IS COVERED AND WHAT IS NOT.

I WISH THERE WERE MORE FUNDS AVAILABLE FOR THE DISABILITY SUPPORT PROGRAMS. ALSO, I WISH THERE WAS A SUPPORT GROUP OR SOMETHING THAT THERE WAS EASY TO ACCESS.

IT IS BETTER NOW THAN IT WAS BEFORE.

I COULD USE A LITTLE MORE HELP AROUND THE HOUSE, SOMEONE COMES IN ONE DAY A WEEK BUT I COULD USE MORE HELP.

THERE ARE SUPPORTS BUT NOT ENOUGH. THINGS I NEED LIKE, WINDOW CLEANING AND YARD WORK ETC ARE NOT COVERED. I AM ONLY ALLOWED 3 SHOWERS A WEEK IN TERMS OF HELP. I HAVE NOT BEEN EVALUATED SINCE 2001 AND COST KEEPS GOING UP AND WHAT I AM ABLE TO DO GOES DOWN. I HAD TO USE MY RRSP FOR MY [] AND THAT WILL PUT MY INCOME UP. NO CONSULTATION, THEY JUST GAVE ME FORMS ALREADY MADE OUT TO SIGN. I WAS GIVEN VERY LITTLE INFORMATION ON SERVICES, JUST ONE GENERAL BROCHURE. NOT VERY PRO-ACTIVE ABOUT DEALING WITH DISABILITY. I WAS TOLD I HAD NEW DSP WORKER, BUT NOT TOLD WHO. NO ONE HAS EVER BEEN TO MY HOUSE.

IT HAS BEEN REAL POSITIVE, HELP PEOPLE WITH DISABILITIES TO HAVE A BRIGHTER OUTLOOK ON THINGS. IT IS NICE TO KNOW THAT YOU CAN HAVE A PLACE TO TURN TO IN THE EVENT OF A CRISIS.

SPECIAL TRAINING AND SUPERVISION, SOMEONE FOR COUNSELLING. WE NEED A PLACE ON PEI LIKE BONNY LEE FARMS. BEHAVIORAL PROBLEMS, DISABILITY PROBLEMS, SPECIAL HELP THAT WE DO NOT HAVE IN PEI. WE NEED THIS AVAILABLE THROUGH THE DSP PROGRAM. A FARM OR SOMETHING. JOB SKILLS COACHING AND TRAINING, WITH SUPERVISION.

DISABLED PEOPLE SHOULD HAVE PARKING PERMITS (I TOLD HER TO CALL DSP AND THEY WOULD PUT HER IN TOUCH WITH PEOPLE WHERE SHE CAN APPLY FOR ONE).

I AM DISAPPOINTED, THEY PROMISE ME THINGS, AND THE PEOPLE THEY HIRE DO NOT DO IT. SHE, THE WOMAN THEY HIRED TO TAKE ME PLACES, MAKES APPOINTMENTS AND THEN CANCELS BECAUSE SHE CANNOT TAKE ME.

I AM GLAD THERE IS THIS PROGRAM. IF I DID NOT HAVE THE HELP WITH HOUSEWORK, IT WOULD BE HARDER FINANCIALLY.

THANKFUL TO HAVE THE SUPPORT BECAUSE WITHOUT IT WOULD HAVE BEEN HARD. IT IS A VERY IMPORTANT PART OF MY RECOVERY. I HAVE ROTARY LIFELINE, ACCESS TO INTERNET, AND SPECIAL TOOLS BECAUSE MY LEFT SIDE IS PARALYZED. TRANSPORTATION IS A PROBLEM BECAUSE I HAVE TO DEPEND ON OTHER PEOPLE.

I WISH THERE WAS MORE MONEY

WORKER CAN BE DIFFICULT SOMETIMES, NOT FRIENDLY AND NOT EASY TO TALK TO.

I WISHED IT WOULD BE MORE THEN \$111. IT IS NOT MUCH, BUT IT HELPS. DIABETES TESTING SUPPLIES COST THAT MUCH, AND MY HOUSEKEEPER IS PAID OUT OF THAT.

THE PEOPLE WHO RUN IT HAVE NO IDEA WHAT IT IS LIKE TO BE DISABLED.

GLASSES, PRESCRIPTIONS ARE VERY EXPENSIVE, SHOULD COME UNDER TECHNICAL AID, IT IS A BARRIER FOR SOME I AM VISUALLY IMPAIRED. THEY SHOULD CONSIDER THE TYPE OF GLASSES (SPECIAL LENSES YOU NEED ARE VERY EXPENSIVE).

MEDICATION IS NOT COVERED UNDER DSP. SOCIAL SERVICE PAYS IT BUT I WORRY ABOUT IF THEY CUT ME OFF

MORE ACCESSIBILITY/TRANSPORTATION TO APPOINTMENTS ETC.

NOT ENOUGH MONEY FOR TRANSPORTATION, SOMETIMES I HAVE TO GO THREE TIMES A MONTH, SOMETIMES 4 OR 5. I CANNOT GO AS MUCH AS I NEED TO, ESPECIALLY IN THE WINTER. MY MEDICATION IS NOT COVERED UNDER DSP EITHER.

MONEY IS A PROBLEM. TRANSPORTATION SHOULD GO UP.

BEFORE THE DSP I WAS NOT GETTING ANY HELP ANYWHERE, I AM HAPPY WITH THAT, I AM GETTING THINGS NOW THAT I WOULD NOT BE ABLE TO AFFORD TO GET ON MY OWN.

ASKED ABOUT SUPPORT BOOTS AND SHOES BUT HAVE NOT HEARD. MONEY FOR MEDICINE.

I WISH SOMEONE COULD TELL ME MORE ABOUT IT AND WHAT IT ENTAILS. I WANT TO KNOW WHAT THERE IS OUT THERE FOR BOTH MYSELF AND MY BLIND DAUGHTER.

IT IS VERY GOOD.

THE PROGRAM NEEDS TO BE MORE ADAPTED TO EACH INDIVIDUAL. OVERALL, I AM VERY HAPPY WITH THE PROGRAM. IT HAS IMPROVED MY LIFE, BUT EDUCATION SHOULD BE ADDED SO YOU CAN IMPROVE YOUR LIFE MORE. TV SHOULD BE LOOKED AT MORE THAN AS ENTERTAINMENT, FOR SOMEONE WHO HAS TO STAY IN BED FOR ALL DAY. THERE SHOULD BE MORE RECOGNITION FOR THE CAREGIVER, THE CAREGIVERS GIVE NEEDS TOO, MY HUSBAND LOOKS AFTER ME 24 HOURS A DAY, 7 DAYS A WEEK, AND HIS NEEDS ARE NOT DEALT WITH. THE CAREGIVERS GET NOTHING, THEY DESERVE MONETARY RECOGNITION AS WELL OTHERS.

I THINK THE DSP IS WONDERFUL

THEY HAVE BEEN DOING WONDERFUL THINGS FOR ME. I WOULD LIKE TO FOCUS ON A COURSE AND MAYBE DSP CAN HELP ME WITH TRAINING, BUILD MY LIFE BACK AGAIN, BUT I NEED TO HAVE THE EDUCATION AND TRAINING SO I CAN MAKE IT HAPPEN. I AM STILL WILLING TO LEARN.

THE DSP STOPS AT 65 ONCE YOU RECEIVE THE OLD AGE PENSION, THAT IS WHAT I AM TOLD.

IT IS A GOOD PROGRAM. I DO NOT KNOW WHAT WE DID WITHOUT THIS PROGRAM.

IT IS HELPFUL.

THEY USED ME.

ASKING FOR A PIECE OF EQUIPMENT REPAIR, AND BEING TOLD WE DO NOT FIX THAT. ASKING FOR EDUCATION FUNDING AND BEING LIMITED TO WHAT I AM ALLOWED TO DO, ONLY A BA IS COVERED, NOT LAW SCHOOL. TWO SUMMER COURSES ARE BEING FUNDED, BUT I AM BEING TOLD THIS IS MY LAST YEAR FOR FUNDING FOR MY

EDUCATION, BUT I AM GOING TO APPEAL IT. THE SUPPORT WORKERS NEED TO BE SENSITIZED, WHEN I TOLD MY WORKER I WAS GOING TO BE A LAWYER, THE SUPPORT WORKER TOLD ME THERE WAS NO PLACE IN SOCIETY FOR BLIND LAWYERS, IT REALLY UPSET ME! I WAS DENIED FUNDING AT FIRST THEN I APPEALED AND GOT SOME, BUT IT IS LIMITED.

MORE ACCESS TO PUBLIC PLACES. MORE FINANCIAL AID FOR ENTERTAINMENT/SOCIAL THINGS. THAT IS WHAT I NEED MOST, SO I CAN GO AND DO WHAT I WANT WITHOUT HELP FROM OTHERS, THEY HAVE LARGE FAMILIES. I DO APPRECIATE EVERYTHING I DO GET.

CAREGIVER ALLOWANCE AND/OR ALLOTMENT FOR RESPITE CARE. IF I MOVED OUT AND GOT ON MY OWN IT WOULD COST THE GOVERNMENT A LOT MORE MONEY. DAY PROGRAMS COMPARED TO RESPITE CARE ARE SO DIFFERENT, DAY PROGRAMS \$1200 A MONTH, AND FAMILY RESPITE CARE IS \$50 A MONTH! IT SEEMS MOST UNFAIR AND FAR OUT OF WHACK! I HAVE NEVER GOT MONEY FROM DSP FOR RESPITE CARE, AND MY FAMILY IS DOING IT ALL UNPAID. IF I HAD TO START LOOKING AT RENT, HEAT, LIGHTS, AND CAREGIVERS, IT WOULD SKYROCKET THE DSP BUDGET RIGHT OUT OF SIGHT. CAREGIVERS ARE GETTING NOTHING FOR IT.

I THINK THIS PROGRAM IS GREAT. BEFORE I MEET THEM MY LIFE WAS JUST MUNDANE AND PLAIN. MY DSP WORKER BROUGHT ME BACK TO LIFE. SHE IS PAID TO TAKE ME OUT ON SATURDAYS.

THE DSP I LIKE. THE SOCIAL SERVICE GUY I WAS WITH WAS BAD TO ME. THE DSP HAVE BEEN GOOD TO ME, THEY GIVE ME A CHEQUE.

I APPRECIATE WHAT THEY GAVE ME. I HAVE ENOUGH NOW, BUT MAY NEED MORE EQUIPMENT SOMETIME IN THE FUTURE. PLEASE NOTE: THIS GENTLEMAN SUGGESTED THAT HE WAS NOT 100% SURE OF WHAT I "WANTED HIM TO SAY" SOMETIMES, BECAUSE FRENCH IS HIS FIRST LANGUAGE. I ASKED HIM IF HE WANTED ME TO REPEAT ANY QUESTIONS, HE SAID NO. I ASKED HIM IF HE WANTED THE SURVEY DONE IN FRENCH, HE SAID "NO, THAT IS OK".

I WISH THEY WOULD HELP US MORE FINANCIALLY, IT IS NOT ENOUGH MONEY FOR THE THINGS WE NEED.

I AM GETTING ENOUGH TO GET BY ON NOW, BEFORE DSP I THOUGHT I WOULD HAVE TO GIVE UP MY HOUSE AND MOVE, WITH THE HELP I AM ABLE TO STAY HERE.

SOME THINGS I NEED ARE NOT COVERED, SOME PILLS FOR MY BAD STOMACH. IS THE SPECIAL BED COVERED, MY DOCTOR WROTE A LETTER BUT I HAVE NOT HEARD ANYTHING AT ALL SINCE LAST FALL.

GLAD TO HAVE THEM THERE WHEN I NEED THEM.

IF THEY CAN HELP OUT WITH THE PROGRAMS IN QUEENS COUNTY, WHERE IS THE MONEY GOING FOR THE PROGRAMS? MONEY HAS TO COME OUT OF OUR POCKETS FOR THESE PROGRAMS.

PROXIES

QUESTION: IS THERE ANYTHING ABOUT THE DISABILITY SUPPORT PROGRAM AND ITS SUPPORTS AND SERVICES THAT YOU WOULD LIKE TO COMMENT ON?

I AM STILL RECOVERING MY HEALTH FROM THE REVIEW PROCESS IN DECEMBER, WE WERE DENIED A COMPUTER. I WAS TOLD BY THEM THAT MY SON COULD COMMUNICATE, FROM PEOPLE WHO NEVER MET HIM, THEY MADE RIDICULOUS DECISIONS ABOUT HIS LIFE WITHOUT EVEN KNOWING HIM. I FELT LIKE I WAS GOING THROUGH THE REVIEW PROCESS WITH THE PEOPLE WHO HAD TURNED US DOWN FOR SERVICES BEFORE. THE REVIEW PROCESS WAS LUDICROUS AND IT HURT MY HEALTH. IT WAS NOT HARD TO WIN THE CASE IN THE END, STRESSFUL, BUT I WAS WELL PLANNED FOR IT.

EVERYTHING IS GETTING SO EXPENSIVE, BUT THE FINANCIAL ASSISTANCE NEVER GETS ANY BETTER, BUT THE OIL GOES UP, HE DOES NOT HAVE AS MANY CLOTHES AS WE NEED FOR HIM. ONE PROBLEM IS THAT THE DSP WORKERS CHANGE SO OFTEN, THEY SHOULD TELL US WHEN A NEW ONE IS STARTING. HOW LONG WILL THIS NEW PROGRAM BE IN EFFECT? WE WERE FORCED INTO THE PROGRAM, I THINK IT IS A WASTE OF THE GOVERNMENTS MONEY THAT WE ARE IN TWO PROGRAMS, INCOME SUPPORT AND DSP.

I DO NOT KNOW WHAT IS AVAILABLE TO ME FOR PEOPLE LIKE MY SON.

FAIRNESS TO CHILDREN INVOLVED. I DO NOT THINK IT IS FAIR THAT IT IS BASED ON PARENTS INCOME. I THINK WE ARE PENALIZED BECAUSE WE WORK HARD AND WE HAVE A DISABLED CHILD. UNDER THE OLD PROGRAM WE RECEIVED FUNDS TO COVER HIS SPECIAL NEEDS, NOW WE ONLY RECEIVE \$500 AND IT LIMITS WHAT WE CAN AFFORD TO DO AS FAR AS SPECIAL NEEDS LIKE RESPITE, SPEECH THERAPY AND HIS A.B.A. PROGRAM. I HAVE A FRIEND WITH TWO AUTISTIC CHILDREN, SHE HAS TO STAY HOME TO LOOK AFTER THEM, BECAUSE OF HER HUSBANDS INCOME THEY RECEIVE NOTHING WHATSOEVER FROM DSP TO HELP THEM, NO RESPITE, NO SPECIAL NEEDS, NOTHING!

BLUE CROSS INSURANCE \$150 A YEAR, WE HAD TO DROP IT. IF SHE LOSES HER HEARING AID DOES THE DSP COVER THAT?

THEY DO NOT HAVE ANY IDEA WHAT DISABILITY THEY ARE DEALING WITH WHEN THEY ARE TESTING, OR THOSE SCALES OR WHATEVER. THAT IS TOTALLY UNACCEPTABLE. THE APPEALS PROGRAM IS ARCHAIC. I HAVE SPOKEN TO MANY PEOPLE WITH THE PROGRAM, AND THEY JUST ARE NOT DOING ANYTHING TO HELP, OR IT DOES NOT SEEM THAT WAY.

THE APPEALS PROCESS IS BIASED, IT IS NOT IMPARTIAL. THE INCOME MEANS TESTING IS VERY UNFAIR AND DEGRADING, THE SCALE ON WHICH THEY DETERMINE SUPPORT IS BASED MORE ON THE PHYSICAL DISABILITIES THAN BEHAVIORAL DISABILITIES.

MEANS TESTING SHOULD BE ELIMINATED, IT IS DISCRIMINATION. IT SHOULD BE COMBINED WITH HIS MEDICAL, BECAUSE HE IS MEDICALLY DISABLED. PARENTS HAVE TO PAY FOR A.B.A. TRAINING TO THE EXTENT THAT THESE KIDS NEED. HIS BABY VACCINES CAUSED HIS DISABILITY. ALSO TALK OF REMOVING DSP WHEN HE REACHES AGE 12. WHICH IS RIDICULOUS, BECAUSE WHEN HE IS AGE 12, HE WILL NOT BE THAT AGE MENTALLY. THEY SYSTEM HAS TO BE TREATED DIFFERENTLY, I DO NOT THINK IT SHOULD BE UNDER SOCIAL SERVICES. IT SHOULD BE FREE UNDER OUR MEDICARE SYSTEM. IT HAS BEEN PROVEN IN COURT, A.B.A. IS MEDICAL TREATMENT, NOT SOCIAL.

TRANSPORTATION - SHE COULD WORK SOMETIME, SHE WOULD BE HAPPIER, BUT SHE CANNOT GET THERE. TRAINING FOR TEACHING HER TO SPEAK, SHE HAS A PROBLEM BECAUSE OF HER DEAFNESS. SCHOOL FOR THE DEAF IN CHARLOTTETOWN WAS TEACHING HER TO SPEAK, BUT SHE WAS PUSHED OUT OF THERE, I WANTED TO FIND OUT WHY SHE WAS SPEAKING, THEN SHE LOST IT BECAUSE THERE WAS A TEACHER'S CHANGE, AND SHE LOST WHAT SHE HAD LEARNED. AND SHE NEVER GOT HER SPEECH BACK. IF THEY HAD ADULT CLASSES IT WOULD BE GOOD.

I DO NOT THINK WE SHOULD HAVE OUR PERSONAL FINANCES PUT ON THE BOARD EVERY YEAR, BUT I WILL GO ALONG WITH IT BECAUSE [] NEEDS THESE PROGRAMS.

I DO NOT REALLY LIKE THE WAY THEY DO IT NOW, BECAUSE WE HAVE TO SAVE MONEY FOR THINGS NOW, AND IT IS HARD.

I THINK THAT THERE IS A LOT MORE WORK FOR IT. I HAVE TO KEEP TRACK OF EVERYTHING MYSELF AND I DO NOT LIKE IT. I LIKED THE OLD ONE BETTER WHERE THEY DID ALL THIS INSTEAD.

IF WE NEED ANYTHING I USUALLY PHONE HER WORKER AND IT IS NO PROBLEM, THEY GET IT FOR ME, (AS LONG AS IT IS NOT TOO EXPENSIVE).

IT IS NOT FAIR FOR A PERSON WHO IS BLIND.

I AM VERY HAPPY AND PLEASED WITH WHAT WE GET.

THE WHOLE DSP IN REGARDS TO THE ILLUSION I HAVE IS THAT PEOPLE DO NOT KNOW WHAT IS AVAILABLE. DSP IS VERY VAGUE, IF YOU ASK IF IT IS OFFERED THEY WILL TELL YOU, BUT IF YOU DO NOT ASK, THEY DO NOT TELL YOU. HOW DO THEY DECIDE WHO IS ASSESSED AND HOW FUNDS ARE DISPERSED? HE HAS FAMILY, IS MOBILE, SOCIAL AND WAS ASSESSED AND GIVEN \$32 BY DSP. I HAVE 30 CLIENTS HERE WHO HAVE YET TO BE ASSESSED. WHO HAVE NO FAMILY, ARE IN WHEELCHAIRS/BED RIDDEN, WHO DO NOT RECEIVE ANY FUNDS FROM DSP AND ARE IN GREAT NEED. AT THE PLANNING MEETING I WAS TOLD WHAT HE WOULD RECEIVE IT WAS ALREADY DECIDED I HAD NO SAY.

ONCE THEY ARE 18, THE PLAN SHOULD CALCULATE THE DISABLED PERSONS INCOME INSTEAD OF THEIR PARENTS. THE AGE IS CURRENTLY 25, WHEN REALLY THEY SHOULD BE USING THE DISABLED PERSONS INCOME BECAUSE LEGALLY THEY ARE ADULTS.

I WISH THAT THEY WOULD LET ME KNOW WHERE WE STAND ON THIS PROGRAM. WE HAVE NOT HAD ANY SUPPORTS AT ALL, SO SOME QUESTIONS WERE NON-APPLICABLE, HOWEVER I AM NOT TOO SURE ABOUT HOW THE PROGRAM WORKS OR WHEN IT CAN START. I WAS INITIALLY TOLD IT WOULD NOT START UNTIL HE WAS 25. I JUST WOULD LIKE SOME MORE INFORMATION ABOUT THIS PROGRAM, AND WHERE [] STANDS IN THIS PROGRAM.

IT WOULD BE NICE TO HAVE MORE INFORMATION ABOUT THE DISABILITY SUPPORT PROGRAM AND WHAT SUPPORTS AND SERVICES ARE AVAILABLE

IT HAS BEEN QUITE A RELIEF FOR US TO HAVE IT. IT USED TO BE QUITE HARD FOR US, BUT THE MONEY THAT SHE RECEIVES FOR ONE TO ONE CARE HAS MADE A BIG DIFFERENCE. I DO NOT WORRY NEARLY AS MUCH ABOUT MONEY NOW AS I USED TO BEFORE THIS PROGRAM STARTED. Q34- SHE ONLY HAS A GRADE 7 OR 8 EDUCATION, SHE WOULD NEED MORE TRAINING THAN SOME PEOPLE, BUT SHE CATCHES ON. Q42- SHE CANNOT DRIVE, AS LONG AS SOMEONE IS AVAILABLE TO TAKE HER. SOMEONE IS AVAILABLE MOST TIMES.

IT IS A WONDERFUL PROGRAM FOR ANYONE WHO NEEDS IT, I APPRECIATE THE HELP I GET, BUT I WORRY ABOUT IT NOT BEING THERE, RO BEING CUT OFF.

ACTUAL TREATMENT FOR AUTISM SHOULD NOT BE COVERED UNDER THE DSP, IT SHOULD BE COVERED UNDER MEDICARE, THERE SHOULD NOT BE AN AGE CUT OFF FOR SUPPORT. THERE SHOULD NOT BE INCOME TESTING IN THE FIRST PLACE. MEDICAL TREATMENT LIKE SPEECH THERAPY SHOULD BE NEEDS BASED, NOT BASED ON INCOME OR HOW MUCH IS IN THE BUDGET, IT SHOULD BE BASED ON THE NEEDS OF THE PERSON. THERE SHOULD BE CLEAR OWNERSHIP BETWEEN THE DEPT OF EDUCATION AND THE DEPT OF HEALTH OVER THE TREATMENT OF HEALTH. [] SHOULD BE CONSIDERED AN ADULT AT THE AGE OF 18, NOT 25, NO AGE DISCRIMINATION.

A \$3000 A MONTH CEILING SHOULD BE ELIMINATED. SOME FAMILIES REQUIRE MORE THAN THAT. SOME FAMILIES REQUIRE MORE THAN THAT DEPENDING ON THE DISABILITY. IT IS \$600 JUST FOR HIS DRUGS, IF HE NEEDS A NEW KIND OF DRUG, THEN IT WILL NOT BE COVERED UNDER THE DSP. ONCE HE REACHES 18, HE HAS TO GO ON WELFARE TO GET HIS DRUGS COVERED. I DO NOT THINK THAT IS RIGHT. IT SETS PEOPLE UP FOR A LIFE OF STAYING IN ONE SPOT. DISABILITY SUPPORTS SHOULD BE COVERED BECAUSE IT IS A MEDICAL CONDITION, FINANCIAL SUPPORT SHOULD BE COVERED UNDER SOCIAL SERVICES. FAMILIES WITH DISABLED PEOPLE ARE BEING PENALIZED.

IT IS GOOD IN THEORY, BUT IT DOES NOT MEET THE NEEDS OF THE CHILD. THE AMOUNT OF ADMINISTRATION AND THE AMOUNT OF MONEY THAT THEY PUT OUT TO RUN THE PROGRAM SHOULD BE PASSED DOWN TO THE PEOPLE WITH DISABILITIES. THE PROGRAM IN THEORY IS GOOD, BUT IT DOES NOT HELP PEOPLE WITH INTELLECTUAL DISABILITIES AT ALL, BUT IT FOCUSES ON PHYSICALLY DISABLED PEOPLE.

THE DSP HAS MADE A BIG DIFFERENCE IN MY LIFE.

I NEVER UNDERSTOOD WHY THEY MADE THE PROGRAM, I WAS GETTING THE MONEY FROM WELFARE AND NOW I GET IT FROM DSP. INSTEAD OF TAKING ONE TO THE BANK I AM TAKING FOUR CHECKS THE SAME BECAUSE I HAVE A SET OF TWINS

I APPRECIATE THE HELP I RECEIVE. BUT I WOULD LOVE TO TAKE THEM SOMEPLACE OTHER THAN ON THE ISLAND. I WOULD LOVE TO TAKE THEM TO A NICE PLACE. I WOULD LOVE TO TAKE THEM TO DISNEYLAND AS THEY BOTH WOULD LOVE IT.

THE PROGRAM IS VERY LIMITED. IT IS DESIGNED IN ONE WAY, IT IS NOT FLEXIBLE TO MEET INDIVIDUAL DISABILITIES. INCOME IS THE BOTTOM LINE, AND THAT IS THE ONLY THING THEY LOOK AT. A HOME WITH ONE DEAF CHILD AND A HOME WITH THREE SEVERELY PHYSICALLY AND MENTALLY HANDICAPPED CHILDREN ARE TWO DIFFERENT SCENARIOS WITH TWO DIFFERENT NEEDS, EVEN THOUGH THE INCOME MAY BE THE SAME.

THERE IS SO MUCH THAT WE NEED, AND WE DO NOT KNOW WE NEED TILL THE TIME ARISES. I FEEL THAT WE SHOULD HAVE BETTER FUNDING FOR PAT AND THE ELEPHANT, BECAUSE IT CAN GET REALLY EXPENSIVE, NOT THAT IT IS NOT AN EXCELLENT SERVICE, IT JUST NEEDS BETTER FUNDING. LIKE ALL PROGRAMS, THEY NEED UPDATING THROUGH TIME AND THROUGH RESEARCH. THE PROGRAM HAS GOTTEN SO MUCH BETTER. AS FOR HOW MUCH MONEY THAT IS RECEIVED MONTHLY, IT IS ACCEPTABLE, BUT IT COULD BE BETTER.

I THINK THE HEALTH CARE ON PEI NEEDS TO BE A LOT BETTER, WE NEED TO GO OFF ISLAND TO NEWFOUNDLAND FOR [] TO RECEIVE THE CARE HE NEEDS, LIKE FOR PHYSIOTHERAPY.

I FIND THINGS HAPPEN A LITTLE SLOWER THAN I LIKE. I REALIZE EVERYTHING TAKES TIME BUT, ON OCCASION THINGS BREAK DOWN AND IT TAKES A LONG TIME TO GET THE MONEY FOR IT. IT SEEMS TO TAKE A LONG TIME TO GET MONEY WHEN NEEDED. []'S EQUIPMENT BREAKS DOWN AND IT IS SLOW TO GET THE MONEY TO PAY FOR THE FIXING OF IT.

MORE SUPPORT IN THE SCHOOL AREA WITH CHILDREN WITH DISABILITIES. I THINK THEY SHOULD HAVE SURROUND SOUND SYSTEMS IN ALL THE SCHOOL.

THE HELP IN THE SCHOOL SYSTEM HAS BEEN CUT BACK AND I DO NOT THINK THEY REALIZE THAT CHILDREN CAN

FALL BEHIND BECAUSE THE SUPPORT IS NO LONGER THERE.

WHAT I HAVE SAID BEFORE ABOUT THE MONEY NOT BEING ENOUGH FOR THE THINGS SHE NEEDS, UNDERWEAR, ETC.

IT HAS CHANGED HER QUITE A BIT, TO BE ABLE TO GO OUT AND BE WITH OTHER PEOPLE, AND SHE SEEMS TO BE MORE OUTGOING.

IT IS PRETTY HARD FOR HER TO GET AROUND UNLESS SHE HAS SOME FORM OF ASSISTANCE.

DSP HAS BEEN A GREAT THING FOR [], BUT I DO WISH IT WAS MORE AVAILABLE, AND INFORMATION ABOUT DSP SUPPORTS AND SERVICES AND UNDER WHAT CONDITIONS THEY WERE GIVEN WERE AVAILABLE.

[] NEEDS TO UNDERSTAND THE PROGRAM IN GENERAL. THE PRESENTATION OF THE PROGRAM HAS BEEN KEPT VERY SECRETEIVE AND IT KEEPS US ALL IN THE DARK. IT WAS A NEW PROGRAM AND OFFERED EVERYTHING AT FIRST AND THEN STARTED TAKING IT AWAY. THESE SERVICES THAT ARE TAKEN AWAY WILL BE ABLE TO MAKE OR BREAK THE DURATION OF HER STAY WHERE SHE IS LIVING.

THE SERVICES THAT WERE ASKED FOR WE NEVER RECEIVED. I FEEL THERE WAS A LACK OF EFFORT IN TRYING TO PUT THOSE SERVICES TOGETHER. WITH THE DSP. THEY SEEM TO LOOK TO PROFIT SERVICES RATHER THAN LOOKING AT THE NEEDS OF CLIENTS. WE NEED TO BE ABLE TO ACCESS ALL SERVICES NOT JUST THE PROFIT ONES.

THE LACK OF SERVICES OFFERED TO HIM. THE PROGRAM IS EITHER AYES OR NO PROGRAM THERE IS NO DISCUSSION AROUND THE NEEDS OR ISSUES.

FROM MY EXPERIENCE, THE PROGRAM ITSELF HAS CHANGED FROM DAY ONE AND WE ARE UNSURE OF IT NOW. PEOPLE ARE NOT EDUCATED ON IT NOW.

I AM GLAD IT IS THERE. I FIND IT IS A GOOD SYSTEM BECAUSE IN OTHER PLACES IT DOES NOT HAPPEN. WE ARE GLAD IT IS THERE, IT MADE OUR LIVES EASIER ESPECIALLY FOR HEARING AIDS AND STUFF LIKE THAT.

I DO NOT THINK ENOUGH WARNING IS GIVEN ON WHEN AND HOW THE DSP CHANGES.

MORE FINANCIAL HELP - HEARING AID REPAIRS, TRANSPORTATION, AND NEED SPECIAL SHOES.

THE SUPPORTS ARE ACCEPTABLE JUST AS LONG AS NOTHING CHANGES. WE ARE MAKING ENDS MEAT NOW, BUT IF PRICES WERE TO RISE THAN I WOULD NEED MORE HELP.

THAT THE PROGRAM HAS REALLY BEEN A LIFESAVER FOR [] AND MYSELF.

I WOULD LIKE TO SEE IT EXPANDED TO COVER MORE THINGS. I WOULD ALSO LIKE TO SAY THAT MY SUPPORT WORKER [], HAS BEEN A GREAT HELP. AND [] HAS BEEN DOING EVERYTHING [] CAN TO GET WHAT [] NEEDS.

I THINK THE SUMMER CAMP SHOULD BE AVAILABLE TO ALL PEOPLE WITH CHILDREN WITH DISABILITIES. FREE OF CHARGE. IF I USE MY RESPITE MONEY FOR THIS CAMP THEN I DO NOT HAVE ADEQUATE FUNDS FOR CHILDCARE FOR THE REMAINDER OF THE MONTH.

THE DSP IS REALLY GREAT AND IT HELPS ME OUT A LOT AND MAKES A LOT OF PEOPLE HAPPY.

THE AGE AT WHICH DSP CONSIDERS HIM AN ADULT SHOULD BE 18 INSTEAD OF 25. THE MEANS TESTING FOR FINANCIAL NEEDS SHOULD BE BASED ON THE DISABLED INDIVIDUAL NOT THEIR FAMILY OR GUARDIAN IF BOTH PARENTS SHOULD PASS AWAY. THE LACK OF FLEXIBILITY IF HE REQUIRES A NEW SERVICE TO BE PUT INTO HIS PROGRAM. LACK OF ASSISTANCE FOR TRAVEL SERVICES THAT ARE NOT AVAILABLE ON PEI, AND FOR MODIFICATIONS TO OUR HOME. THE LACK OF AN APPROPRIATE VEHICLE. LACK OF ASSISTANCE FOR SPECIALIZED HOMECARE OR CHILD CARE FOR AFTER SCHOOL.

PART OF THE PROGRAM STATES THAT THERE CAN BE DOLLARS FOR SOCIAL NEEDS, YET WHEN YOU TRY TO ACCESS THE DOLLARS IT IS DENIED. ESPECIALLY FOR [] WHO NEEDS MORE OF A SOCIAL SUPPORT AND SOMEONE TO BE THERE AND HELP HER BECAUSE HER MOBILITY IS NOT WELL.

I DO NOT AGREE WITH THE WAY THEY ARE TESTING THE INCOME. IF SOMEONE IS UNDER 25 THEN THE FAMILIES INCOME IS COMPARED, ONLY IF THE PERSON IS OVER 25 IS THEIR INCOME COMPARED.

IT'S JUST STARTING TO GET GOOD, I DON'T FEEL THAT I SHOULD HAVE TO PAY A PERCENTAGE OF THE COSTS, ESPECIALLY CONSIDERING THAT A LOT OF THE THINGS THAT HE NEEDS, NOT WANTS BUT NEEDS, AREN'T COVERED.

I WOULD LIKE NICER THINGS FOR [] AND A PAIR OF DENTURES.

THE MAIN THING IS THAT WE ARE HELD FINANCIALLY RES UNTIL HE IS 25. IT IS UNFAIR AND NOT RIGHT. B/C OF IT, [] MISSES OUT ON SERVICES B/C WE CAN'T AFFORD TO HELP OUT. SECONDLY, THERE ISN'T ENOUGH MONEY COMING IN FOR HIM. LAST FALL, IT TOOK US THREE MONTHS TO PERSUADE HIM TO USE RESPITE CARE, WHEN HE FINALLY AGREED, THEY PULLED RESPITE CARE FROM HIM. THE ONLY GROUPS THAT THEY HAVE TOLD US ABOUT ARE GROUPS THAT HE IS TOO HIGH FUNCTIONING FOR, HE DOESN'T FIT. HE PICKS UP THE OTHER CHILDREN'S BAD HABITS. THE WORKERS ARE NICE, BUT I DON'T THINK THEY REALLY UNDERSTAND WHAT [] HAS.

YEARLY REVIEW WAS LATE BEING DONE, AND WE ARE ALMOST 3 MONTHS WITH NO MONEY FROM THE DSP. IT IS NOT THE DSP WORKER'S FAULT, IF THERE WAS MORE HELP, NOT SO OVERBOOKED WITH CLIENTS, IT WOULD NOT BE THAT WAY. FOR SOME PEOPLE THIS WOULD BE VERY, VERY DIFFICULT FINANCIALLY FOR THEM. ALSO - I HAD A BOARDER HERE THAT THEY PAID ME \$470 A MONTH FOR, BUT BECAUSE [] IS MY SON, THEY ONLY PAY ME \$307 FOR HIM. THEY HAVE BEEN GOOD THOUGH, THEY GOT A MATTRESS FOR HIM, AND GYM, AND THE SUMMER PROGRAM TOO. BUT THAT COSTS ME A LOT OF EXTRA MONEY TOO FOR THINGS LIKE THEY TAKE THEM TO.

I WOULD JUST LIKE TO THANK THE PEOPLE WHO ARE DOING WHAT THEY CAN FOR US, IT REALLY HELPS US.

WHEN HE IS 25 HE GETS MORE COVERAGE, BECAUSE THEN THE DSP CONSIDERS HIM AN ADULT. NOW THAT HE IS ONLY 22 CERTAIN THINGS ARE NOT AVAILABLE TO HIM. ANYWHERE ELSE YOU ARE AN ADULT WHEN YOU REACH AGE 18. I DO NOT THINK THIS IS RIGHT.

DSP SHOULD LET YOU KNOW WHAT IS AVAILABLE, PARENTS SHOULD NOT HAVE TO ASK WHAT IS AVAILABLE. SOME WORKERS KNOW, SOME DO NOT. UNLESS YOU FIND OUT FROM OTHER PARTICIPANTS OR PARENTS WHAT IS AVAILABLE YOU HAVE TO GO WITHOUT.

I THINK THE PROGRAM IS A GOOD PROGRAM. SOME PEOPLE DO NOT HAVE A REAL UNDERSTANDING OF IT, IT SEEMS TO BE FAIR AND ADEQUATE AND OTHER SUPPORTS ARE THERE. I FIND IF YOU HAVE A PROBLEM, YOU CAN TALK TO THEM, THEN ONCE YOU EXPLAIN WHAT YOU NEED, AND IF IT IS AVAILABLE, THEN THE SUPPORT WORKER WILL GET IT. PEOPLE DO NOT UNDERSTAND WHAT IS AVAILABLE AND THEY DO NOT ASK HOW THEY QUALIFY OR IF THEY QUALIFY.

THE FACT THAT THERE IS A MAXIMUM AMOUNT THAT YOU CAN GET PER DISABILITY. IF SHE HAD 2 DISABILITIES, I COULD GET MORE SUPPORT, BUT THE DISABILITY THAT SHE HAS IS A VERY EXPENSIVE THING TO DEAL WITH. THERE SHOULD BE AN ALLOWANCE THAT IF SOMEONE HAS ONE DISABILITY BUT IT COSTS JUST AS MUCH AS 2, THEY SHOULD BE ABLE TO RECEIVE MORE MONEY OR SUPPORT.

THEY COULD USE A FEW MORE SPEECH THERAPISTS, WE FIND IT TRICKY TO GET HIM AS MUCH SPEECH THERAPY AS HE NEEDS.

THE COST CAN BE VERY EXPENSIVE FOR THE LARGE ITEMS THAT HE REALLY NEEDS, LIKE THE MANUAL WHEELCHAIR.

THE PROGRAMS LACK OF ABILITY TO HELP PEOPLE WITH DISABILITIES ACHIEVE EMPLOYMENT.

[] WANTS TO BE SELF-SUFFICIENT AND NOT RECEIVE MONEY FROM THE GOVERNMENT. THE SUPPORTS FOR MENTAL DISABILITIES ARE DIFFERENT THAN THOSE WITH PHYSICAL DISABILITIES, AND THESE ASPECTS NEEDS TO BE LOOKED AT. ANY COMPLAINT THAT I HAD, I WOULD ADDRESS MY WORKER BECAUSE SHE WOULD DO THE BEST THAT SHE COULD WITHIN THE PARAMETERS OF THE PROGRAM, BUT THE PARAMETERS ARE THE PROBLEM. THE COPAY FOR CERTAIN ACTIVITIES FOR [] IS NOT FAIR. THE GOVERNMENT KNOWS THEY DO NOT WORK, AND THE LACK OF MONEY THAT THEY RECEIVE.

IF THEY COULD BE MORE ACTIVE IN TELLING US WHAT IS AVAILABLE FOR HIM. WE DO NOT KNOW IF WE HAVE ANY RIGHT TO ASK, BECAUSE WE DO NOT KNOW WHAT IS AVAILABLE OR WHAT TO EXPECT, OR QUITE WHERE WE STAND.

I THINK THE BIGGEST ISSUE WE HAVE IS THE AGE DISCRIMINATION.

I THINK THAT PEOPLE NEED TO BE AWARE OF THE DIFFERENCE IN PHYSICAL AND BEHAVIORAL DISABILITIES AND BEING ACCEPTING OF THEM. SINGLE PARENTS DO NOT GET CONSIDERED FOR MORE SUPPORT, BECAUSE THEY HAVE TO DEAL WITH THE DISABLED PERSON THEMSELVES. ALSO, SINCE I HAVE TWO OTHER CHILDREN AND ONLY [] GOES TO THE RESPITE CARE, I DO NOT GET A CHANCE TO REGENERATE, BECAUSE I AM STILL LOOKING AFTER THE OTHER TWO.

IT IS A GOOD THING THAT HAS HAPPENED. WE GOT BABYSITTING HOURS AND RESPITE CARE, AND SOME MONEY FOR OUTINGS. I THINK IT WAS A GOOD THING TO HAPPEN.

THAT THE PROGRAM SEEMS TO BE GEARED TOWARDS THE PHYSICALLY DISABLED AS OPPOSED TO MENTALLY DISABLED PEOPLE. THE LEVEL OF SUPPORT IS LOWER THAN WHAT IT SHOULD BE FOR PEOPLE WITH SEVERE MENTAL DISABILITIES, LIKE [] HAS. THERE IS NO EXPERTISE FOR ADULTS WITH AUTISM AND COMMUNICATION AIDS ARE NOT NECESSARILY COVERED UNDER DSP.

IT SEEMED RIDICULOUS BECAUSE AT THE TIME THERE WAS A SUPPORT WORKER AND A SOCIAL WORKER AND THEY WERE ALL DOING THE SAME THING. I LIKE MY SUPPORT WORKER A LOT, SHE HAS DONE A GREAT JOB. BUT I FEEL THAT IT WAS JUST MAKING MORE WORK FOR GOVERNMENT WORKERS AND IT WAS A WASTE BECAUSE ONE WORKER WOULD DO THE WORK AND THE NEXT WOULD COME IN AND DO THE SAME THING AS THE FIRST. IT WAS JUST KIND OF A WASTE OF TIME.

I JUST FOUND OUT THAT ANYBODY WHO IS A CLIENT OF DSP, IS NOT DEEMED AN ADULT UNTIL THEY REACH 25. I DO NOT AGREE WITH THIS AT ALL, BECAUSE I THINK THAT THAT IS SOMETHING THAT A DOCTOR SHOULD DECIDE, NOT THE GOVERNMENT BECAUSE EVERYONE IS DIFFERENT.

HIS SUPPORT WORKER AND THE PROGRAM ITSELF IS GREAT. BUT THE BIG ISSUE IS THE TRANSPORTATION, BECAUSE WHEN THEY TELL YOU NO AND YOU DO NOT HAVE A VEHICLE, HOW DO YOU GET A CHILD IN A WHEELCHAIR AROUND? THAT WAS REALLY ALL THAT I WAS WONDERING ABOUT.

FOR THE AMOUNT OF TRAVELLING WE DO WITH HER, WE LIVE 2 HOURS FROM MOST OF HER APPOINTMENTS, SO WE WOULD LIKE SOME HELP WITH THAT, LIKE THE GAS COSTS.

THE CHANGES ARE NOT HELPING US AT ALL AND I AM NOT SURE WHAT THIS YEAR IS GOING TO BRING FOR US.

THERE IS A LOT OF PEOPLE IN THIS PROVINCE WHO NEED TRANSPORTATION SERVICES AND WHO ARE NOT RECEIVING THEM. ALSO THERE SHOULD BE SOME KIND OF ADULT CARE/HOUSING FACILITIES.

I HAVE NOT HAD TO ACCESS THEM FOR ANYTHING BECAUSE WE ARE FAIRLY INDEPENDENT. I THINK THAT PUBLIC TRANSPORTATION SHOULD BE MORE AVAILABLE. I KNOW THAT IF [] WAS ON HIS OWN HE WOULD NOT BE ABLE TO MAKE IT WITH THE AMOUNT OF MONEY HE GETS MONTHLY. A LITTLE MORE MONEY IS ALWAYS GOOD. THIS SURVEY HOWEVER WAS A LITTLE TOO REPETITIVE, AND A LOT OF THE QUESTIONS DID NOT REALLY APPLY TO ME, HOWEVER I STILL AM FAIRLY NEW TO THIS PROGRAM.

THE FACT THAT YOU CAN PUT SOMEONE IN A GROUP HOME WITH [] DISABILITY AND SPEND HUNDREDS OF THOUSANDS OF DOLLARS ON THEM, BUT THEY EXPECT FAMILY MEMBER TO DO IT FOR 12 THOUSAND DOLLARS. I AM VERY UNHAPPY ABOUT THE CHANGES THAT HAVE TAKEN PLACE IN THE SHERWOOD HOME WHERE [] PRESENTLY GOES. IT WAS ALWAYS UNDER THE UMBRELLA OF MENTAL HEALTH, WITH A RATIO OF 1 EMPLOYEE TO EVERY 4 CLIENTS, BUT NOW IT HAS CHANGED TO CONTINUING CARE, IN WHICH THE RATIO IS 1-8. I AM NOT HAPPY THAT IT WAS NOT EVEN BROUGHT TO FAMILY MEMBERS ATTENTION EARLIER.

I FEEL THERE SHOULD BE MORE LIAISON WITH TREMPLOY AND QUEENS CO. RESIDENTIAL SERVICES, AND GROUP HOMES BETWEEN THEM AND THE DSP, BECAUSE CAREGIVERS HAVE INFORMATION BUT THE OTHERS DID NOT HAVE PROPER INFORMATION, ON HOW FUNDING WAS GOING TO WORK, ETC.

IT MAKES ME UNHAPPY THE WAY THEY SET THE PROGRAM UP THAT A PERSON THAT WAS ON MEDICATION FOR 15 YEARS AND DENTAL EXPENSES WAS CUT OUT, AND HOW THEY BASE THE AMOUNT OF SUPPORT IS NOT EXPLAINED TO PEOPLE.

THE FINANCIAL ASSISTANCE IS ACCEPTABLE BUT ONLY JUST. IT IS A 24/7 JOB TO LOOK AFTER []. AS FAR AS THE PROGRAM IS CONCERNED, IT HAS ONLY BEEN A FEW MONTHS AND THEY ALL DECIDED TO NOT INTRODUCE ANYTHING NEW UNTIL [] SETTLES DOWN IN HIS NEW HOME AFTER BEING AT HOME WITH HIS MOTHER ALL HIS LIFE. THE REAL TEST WILL COME AFTER I SEE WHAT THE DSP IS WILLING TO DO FOR [] IN THE FUTURE.

I NEVER HAD ANY PROBLEMS, WHATEVER HE NEEDED HE GOT, I AM VERY SATISFIED.

WHENEVER THEY SAY SUPPORT, IT WOULD BE NICE IF THEY WOULD MEAN SUPPORT. I WOULD LIKE TO BE INFORMED WHAT SERVICES AND SUPPORTS ARE AVAILABLE. MY SUPPORT WORKER IS STILL LEARNING HERSELF, SO SHE CANNOT TELL ME A LOT OF THE THINGS I WOULD LIKE TO KNOW, BUT SHE DOES TRY TO GET ALL THE INFORMATION SHE CAN FOR ME.

WE NEED MORE LOCAL PROGRAMS AND TRANSPORTATION IS A BIG PROBLEM NOTE: [] HAS WORKED AT THE

WORKSHOP "FOR AGES" BUT SHE WAS NOT ABLE TO PUT A NUMBER OF MONTHS ON IT.

HE WOULD REALLY BENEFIT FROM A ONE ON WORKER AND GREATER MOBILITY. ALSO, THE ADDITIONAL JOB TRAINING HE RECEIVED WAS THROUGH THE WORKSHOP. THE VOLUNTEER TRAINING WAS THROUGH THE WORKSHOP AND WITH A STUDENT DOING HER OJT, NOT THROUGH THE DSP.

I WOULD LIKE TO SEE HER GET OUT MORE, BECAUSE WHENEVER SHE GOES OUT IT IS ONLY FOR THE WORKSHOPS (WHICH IS NOT TOO OFTEN). ALSO, I CANNOT TAKE HER OUT OTHER THAN THAT. I HAVE HAD CANCER IN MY LEG AND I WALK WITH A CANE, IT IS VERY HARD TO TAKE HER OUTSIDE AT ALL BECAUSE THE MUSCLE IN MY LEG IS NOT WHAT IT USED TO BE. I LET HER WALK TO THE STORE BEFORE (IT IS JUST UP THE ROAD) AND SHE BOUGHT SOME SCRATCH TICKETS AND THE CHILDREN TOOK THEM FROM HER. I WOULD LIKE SOMEONE TO COME OUT AND SPEND SOME TIME WITH HER AND TAKE HER OUTSIDE SO SHE IS HAPPIER.

THE PROGRAM SHOULD BE ABLE TO COVER THE CHILDREN'S MEDICATION. IT SHOULD NOT MATTER WHETHER YOU ARE OR ARE NOT ON WELFARE. IT SHOULD NOT BECOME A BURDEN TO TRY AND COVER THAT EXPENSE.

THEY ARE AMAZING, I AM QUITE HAPPY WITH THE PEOPLE INVOLVED IN IT, I JUST WISH THAT THERE WAS MORE MONEY AVAILABLE FOR THERAPY. I WOULD LIKE TO SEE HIS THERAPY HOURS DOUBLED IN A WEEK. I THINK IT WOULD BE EASIER TO KEEP THERAPISTS IF THEY WERE PAID MORE OR GIVEN MORE BENEFITS. THE HARD PART IS FINDING GOOD QUALIFIED THERAPISTS. ALSO, IT TAKES 30MIN TO GO INTO TOWN AND WHEN YOU ARE ONLY GOING FOR A 4 HOUR THERAPY SESSION IT GETS KIND OF RIDICULOUS BECAUSE OF HOW MUCH YOUR PAYING FOR GAS AND THE WASTE OF IT.

IF THEY HAD PROGRAMS THAT [] COULD ATTEND IN THE EVENING.

I THINK IT IS A LOT BETTER THAN IT WAS. I GET MORE RESPITE DAYS NOW, AND THAT IS A BIG HELP. I GET MORE MONEY, SO IF I NEEDED TO GO SOMEWHERE, I HAVE MORE MONEY TO PAY SOMEONE TO COME IN AND TAKE CARE OF HER, AND THAT MAKES IT A LOT EASIER.

I WISH BOTH THE GIRLS I LOOK AFTER FOR WOULD GET 5 HOURS A DAY WITH A ONE ON ONE WORKER.

IF A CHILD HAS A DISABILITY IT DOES NOT MATTER HOW MUCH THE FAMILY MAKES OR HOW OLD THE DISABLED CHILD IS, THERE SHOULD BE SUPPORT OUT THERE NO MATTER WHAT THE SITUATION IS.

I HAVE 2 BOYS, AND I HAVE BEEN VERY FORTUNATE WITH MY SERVICE FROM THE DEPARTMENT. I FEEL I HAVE BEEN VERY LUCKY WITH THEM. IF I DID NOT HAVE THE SUPPORT, THE BOYS WOULD NOT BE WITH ME AND I REALLY FEEL THAT I HAVE BEEN REALLY LUCKY.

THEY GO BY OUR INCOME, WHICH I DON'T THINK IS FAIR, IT SHOULD GO BY THE CHILD'S NEED/DISABILITY.

I DO NOT KNOW WHAT IS AVAILABLE, NO CHOICES, THIS IS WHAT HE GETS AND THAT IS IT. THE PAPERWORK REQUIRED RE: RECORD OF DOCTOR APPOINTMENTS AND RESPITE CARE, SO I CAN GET PRIOR APPROVAL FOR THOSE EXPENSES, SPECIAL TRIPS NEED TO BE REAPPLIED FOR EACH AND EVERY TIME, IT IS RIDICULOUS. I AM JUST TOO BUSY TO DO THE PAPERWORK, SO I PAY FOR IT MYSELF, I GET TIRED OF FIGHTING WITH THEM, SO I DO NOT BOTHER ANYMORE. HE GETS \$700 A MONTH BECAUSE HE IS LIVING WITH ME, BUT IF HE LIVED WITH MY NEIGHBOUR THEY WOULD GET MUCH MORE, I AM LOSING BECAUSE I AM HIS FAMILY.

I WOULD LIKE TO GET MORE SUPPORTS FOR HIM AT SCHOOL BECAUSE HE DOES NOT GET A LOT OF SUPPORTS. THEY SUPPORT HIM A LITTLE, BUT IT IS GETTING REALLY HARD. I HAD TO KEEP HIM HOME FROM SCHOOL FOR A MONTH BECAUSE IT IS GETTING SO DIFFICULT. WE GOT HIM A TUTOR AND THAT SEEMED TO HELP A LITTLE, BUT I NEED SOMEONE THAT CAN SUPPORT HIM ONE ON ONE ALL THE TIME. THERE IS LOTS THAT CAN BE DONE, BUT WE CANNOT DO IT FOR HIM BECAUSE WE DO NOT HAVE THE MONEY. I WORRY ABOUT HIM WHEN HE IS AT SCHOOL JUST IN CASE ANYTHING WERE TO HAPPEN, LIKE HE GETS PUSHED OR SOMETHING LIKE THAT.

[] SUPPORTS HAVE BEEN WONDERFUL, HOWEVER WE DO NOT KNOW WHAT WILL HAPPEN IN THE FUTURE. WE DO NOT USE RESPITE CARE AS MUCH AS OTHERS, BUT WE ARE DOING WONDERFUL, FOR NOW ANYWAYS.

IT IS NOT UNIVERSAL, EACH PERSON IS NOT TOLD WHAT THEY CAN RECEIVE, THEY ARE ASKED WHAT THEY NEED. THEY ARE NOT FAIR TO THE PARENTS WHO ARE BEING THE MAIN CAREGIVERS OF THE DISABLED PERSON, A PERSON WHO IS NOT A FAMILY MEMBER WOULD RECEIVE A LOT MORE ASSISTANCE AND A LOT MORE FINANCIAL ASSISTANCE. WE DO NOT KNOW WHAT WE ARE ENTITLED TO. I THINK I WOULD LIKE TO SEE AN ADVOCATE THAT WOULD HELP THEM WITH PLANNING THINGS LIKE WILLS, ESTATE PLANNING. I FEEL THIS QUESTIONNAIRE IS ALL ONE SIDED - BECAUSE YOU ONLY HAVE ONE POINT OF VIEW BECAUSE YOU DO NOT KNOW ALL YOUR OPTIONS.

I DO NOT THINK THAT WE SHOULD BE MADE TO PARTICIPATE IN IT IF WE CANNOT, IT PUTS A LOT OF PRESSURE ON A PERSON. WE HAVE NO CHOICE, IF I DECIDE I DO NOT WANT TO DO IT ANYMORE, THEN WE LOSE EVERYTHING AND DO NOT GET ANY HELP AT ALL.

WE ARE WORRIED THAT THERE WILL BE NOTHING FOR HIM TO DO IN 2 YEARS WHEN HE IS FINISHED WITH SCHOOL, THERE IS A LACK OF PROGRAMS AVAILABLE FOR ADULTS WITH DISABILITIES/NO VACANCIES IN PROGRAMS. WE ARE VERY HAPPY WITH THE ASSISTANCE THAT WE GET, BUT AS WE GET OLDER, WE WILL REQUIRE MORE AND MORE HELP. WHEN THEY LOOK AT OUR INCOME TO DECIDE ON FINANCIAL ASSISTANCE, THEY LOOK AT LAST YEARS 2002 INCOME, BUT THIS YEAR, BECAUSE OF A HEART CONDITION, I AM TAKING HOME 60% LESS, SO THERE WAS A BIG CUT. I DO NOT AGREE WITH THE AGE BEING SET AT 25, IT SHOULD BE 18.

I AM QUITE SATISFIED WITH THE PROGRAM.

I WORRIED ABOUT WHAT WILL HAPPEN WHEN HIS PARENTS GET MUCH OLDER AND WHETHER THE HELP WILL BE THERE FOR []. [] WAS VERY AFFECTED BY THE CLOSURE OF KINGSWOOD CENTRE AND THE GOVERNMENT IS SLOW TO STRAIGHTEN THAT OUT. WE DO NOT LIKE THE CHANGE FROM THE GOVERNMENT PAYING TO THE FAMILY PAYING.

BECAUSE OF [] LACK OF CONTROL AND IMPULSES I HAVE A HARD TIME FINDING SOMEONE TO BE WITH HIM. THIS PAST COUPLE OF MONTHS I HAVE HAD TO TAKE MEDICAL LEAVE OF ABSENCE BECAUSE I COULD NOT FIND ANYONE TO HELP. I HAVE NOT HAD RESPITE FOR OVER A YEAR AND NEITHER HAS MY HUSBAND. I DO NOT UNDERSTAND WHY THERE CANNOT BE SOMETHING MORE LOCALIZED. I DO NOT KNOW HOW TO SAY IT ALL. THE PEOPLE FROM THE RESPITE SAY THAT I NEED RESPITE BUT THEY NEVER GIVE ME ANY. IT SEEMS TO BE A BIG ISSUE BECAUSE OF THE HOURS THAT MY HUSBAND AND I ARE SUPPOSED TO WORK...I HAVE JUST BEEN REALLY UPSET WITH IT ALL.

I REALLY LIKED IT WHEN [] AND I FINALLY HAD A CHOICE WHERE [] WENT BECAUSE THE PLACE SHE WAS IN BEFORE WAS NOT TEACHING HER ANYTHING. I LOOKED INTO IT AND HAD HER SWITCHED WITH THE DSP'S HELP AND NOW SHE IS A WHOLE NEW WOMAN AND IT HAS HELPED HER A LOT. I HOPE THEY KEEP IT BECAUSE I DO NOT WANT TO SEND HER BACK TO THE OTHER PLACE.

THE PROGRAM SHOULD IDENTIFY CHILDREN FROM EARLIER AGES. THE NURSES VISIT (ONE MONTH AFTER THE BIRTH) SHOULD HAVE A FOLLOW UP VISIT AND AN ASSESSMENT VISIT LATER ON IN THE CHILD'S DEVELOPMENT SO PARENTS ARE AWARE THAT THEIR CHILD MAY NOT BE PROGRESSING AS FAST AS THE SHOULD BE. THE EARLIER PARENTS AND DOCTORS ARE AWARE OF WHAT IS GOING ON, THE BETTER CHANCES OF BETTER PROGRESS RESULTS LATER IN LIFE AS THE CHILD DEVELOPS.

I LIKE THE IDEA THAT THEY ARE ABLE TO HAVE THEIR HELP, HE WOULD REALLY LIKE TO BE ABLE TO GO OUT MORE OFTEN THOUGH.

I THINK THEY DO A GOOD JOB, BUT AS I SAID BEFORE, IT WOULD BE BETTER IF HE HAD A WORKER DURING THE NIGHT TO STAY WITH HIM.

SOMETIMES AS A PARENT I FEEL THAT MAYBE DISORDERS LIKE AUTISM SHOULD NOT COME UNDER A SOCIAL SERVICE PROGRAM IT SHOULD BE UNDER A HEALTH PROGRAM. IT IS HARD TO GO IN AND TALK TO SOMEBODY TELLING THEM HOW HARD YOUR LIFE IS AND PRETTY MUCH BEG FOR THE MONEY. IT DOES NOT SEEM NATURAL. I DO NOT WANT TO SEEM GREEDY OR ANYTHING, BUT I WOULD LIKE TO HAVE A STANDARD LIST OF SERVICES THAT ARE COVERED UNDER THE PROGRAMS, SOMETIMES IT IS HARD TO ACCESS SERVICES BECAUSE YOU HAVE TO DO THE GROUND WORK WHICH IS HARD. EX. RESPITE CARE, YOU HAVE TO FIND THE RESPITE WORKER YOURSELF AND THAT CAN TAKE MONTHS.

PARENTS/CAREGIVERS SHOULD GET PAID FOR THEIR WORK. IF THEY HAD TO GO TO AN INSTITUTION OR GROUP HOME IT WOULD COST A LOT MORE. WE LOOK AFTER THEM 24 HOURS A DAY, 7 DAYS A WEEK.

A LOT OF THESE QUESTIONS DID NOT PERTAIN TO [] BECAUSE HE NEEDS FULL ONE TO ONE CARE ALL OF THE TIME FOR EVERYTHING. HE CANNOT DO ANYTHING REALLY FOR HIMSELF.

THE DSP PROGRAM SEEMS TO BE TAILORED TOWARDS ADULTS WITH DISABILITIES AND PHYSICAL DISABILITIES AND IT NEEDS TO BE INCLUSIVE OF CHILDREN WITH DISABILITIES, ESPECIALLY MENTAL AND INTELLECTUAL DISABILITIES. THE "MEANS"(INCOME) TESTING IS NOT WORKING, THEY TEST ON THE MINIMUM REQUIRED HOURS FOR BEHAVIORAL THERAPY, THEY SHOULD "MEANS" TEST ON THE MAXIMUM HOURS IF ANYTHING AT ALL. NEEDS SUCH AS SPECIALIZED ARE NOT CONSIDERED A NEED AND SHOULD BE. SEVERAL BIOLOGICAL TREATMENTS SUCH AS VITAMINS THAT ARE NOT COVERED AND WHEN CHILDREN GET TO SCHOOL THERE IS NO SPEECH OR OCCUPATIONAL THERAPY AVAILABLE.

I THINK THE DSP IS TOTALLY 90% GEARED TOWARDS PEOPLE WITH PHYSICAL DISABILITIES, NOT TO MENTAL AND INTELLECTUAL DISABILITIES AND NOT TO CHILDREN. I THINK THE "MEANS"(FINANCIAL) TESTING IS INAPPROPRIATE. THE DSP DOES NOT COVER A LOT OF THINGS THAT ARE FOUND IN CHILDREN WITH AUTISM, LIKE VITAMIN SUPPLEMENTS. THE SPECIALIZED CHILD CARE IS NOT CONSIDERED A NEED, EVEN THOUGH SPECIALISTS TELL US WE NEED IT, AND IT IS COSTLY.

I WAS PLEASED TO GET THE EXTRA RESPITE MONEY, BUT I AM DISAPPOINTED IN THE DISCRIMINATION WITH THE AGE, I THINK THAT IS DISGUSTING, IF YOUR 18, YOU ARE AN ADULT.

PEOPLE DO NOT KNOW OR UNDERSTAND THIS PROGRAM. THE CASE WORKERS DO NOT KNOW WHAT IS GOING ON. IF YOU TALK TO ONE, THEN ANOTHER ONE SAYS A DIFFERENT THING. THE WORKERS ARE SO DIFFERENT AND HAVE DIFFERENT STANDARDS. THEY NEVER RETURN PHONE CALLS. []'S WORKER DOES NOT EVEN TALK TO HIM. THEY SHOULD HAVE A SURVEY FOR THE CAREGIVERS AND HOW THINGS HAVE CHANGED FOR US UNDER THIS PROGRAM. THEY CUT FUNDING SO WE CANNOT EVEN GET RESPITE. BACK WHEN IT WAS THE QCRS IF YOU HAD A PROBLEM THEY WOULD FIX IT OR IF THEY COULD NOT FIX IT, THEY WOULD FIND SOMEONE WHO WOULD. WE DO NOT GET ANY BREAKS ANYMORE.

IT HAS BEEN A GOD SEND FOR HER, JUST THE LITTLE EXTRA, IT IS JUST ENOUGH.

I DO NOT AGREE WITH THE FACT THAT PEOPLE UNDER THE PROGRAM ARE NOT CONSIDERED ADULTS UNTIL THEY TURN 25. IT DOES NOT APPLY TO ME, BUT I DO NOT AGREE WITH IT. ALSO, I DO NOT REALLY KNOW VERY MUCH AT ALL ABOUT THE PROGRAM. I THINK THAT THERE SHOULD BE MORE INFORMATION AVAILABLE TO US ABOUT THE PROGRAM. [] GETS A CHEQUE EVERY MONTH, AS FAR AS I KNOW, THAT IS ALL SHE CAN GET. I DO NOT KNOW ANY OF THE SUPPORTS OR SERVICES THAT ARE AVAILABLE TO HER, SO SHE IS MISSING OUT.

JUST THE GRANDFATHER CLAUSE, IF ONE PERSON CAN GET FUNDING FOR GOING TO DOCTORS APPOINTMENTS, MEDICINE THE WAY THEY ASSESS THEM, I CAN'T REALLY

I THINK THAT PARTICIPANTS OF THE PROGRAM SHOULD BE LOOKED AT ON MORE OF AN INDIVIDUAL CASE. THERE IS NOT ENOUGH MONEY THERE FOR THE PEOPLE TO BE COMFORTABLE WITH, IF YOU NEED ANYTHING EXTRA AT ALL YOU PRETTY MUCH HAVE TO BEG FOR IT, AND I AM NOT PLEASED AT ALL WITH THIS. AND FOR QUESTION 80 MY PROBLEM WAS NEVER FIXED, THEY JUST TOLD ME THAT THIS WAS THE WAY THINGS WERE.

THE SUPPORT WORKER HAS TRIED TO GET HER ONE ON ONE SUPPORT BUT IT IS REALLY HARD TO FIND SOMEONE TO DO IT.

LACK OF INDIVIDUALIZED ATTENTION. HE IS BEING GROUPED IN WITH OTHER PEOPLE, AND THEY ARE NOT TAKING HIS NEEDS INTO CONSIDERATION. HE IS BARELY GETTING BY ON WHAT HE IS GETTING, HE SHOULD BE GETTING MORE SUPPORT.

IT HAS BEEN VERY POSITIVE. SHE GETS FUNDING EVERY MONTH.

I GUESS THE THING I HAVE BEEN CONCERNED ABOUT IS THE AGE CUT OFF. I FIND THAT IT IS DISCRIMINATING TO SAY THAT PEOPLE ARE NOT CONSIDERED AN ADULT (IN TERMS OF THIS PROGRAM) UNTIL THEY ARE 25.

THE CAP OF \$36000 IS TOO LOW FOR PEOPLE WITH SEVERE DISABILITIES. THIS FORCES A POOR LIFESTYLE OR A MOVE TO INSTITUTIONAL FACILITY. THERE ARE NO ADULT AUTISM PROGRAMS, THERE IS NO ONE TO DESIGN PROGRAMS OR TO TRAIN OR SUPERVISE WORKERS FOR AUTISM SO THE PARENTS ARE EXPECTED TO DO THIS AND THAT IS TOO HARD. THE PROGRAM PUTS IMPOSSIBLE DEMANDS ON THE PARENTS OF 18-24 WITH SEVERE DISABILITIES. THEY ARE EXPECTED TO MAKE EXORBITANT CONTRIBUTIONS WHICH IS DISCRIMINATORY AS SOMEONE WITH LESSER DISABILITY COULD LIVE SOMEWHERE ELSE AND GET SUPPORT. THE T-5 SLIPS WERE INACCURATE.

THERE ARE SOME HUMAN RIGHTS ISSUES. THE AGE, IT WAS 18 AND NOW THEY SAY THAT THEY ARE RAISING IT TO 25. YOU ARE ABLE TO VOTE WHEN YOU ARE 18, BUT IF YOU HAVE AN INTELLECTUAL DISABILITY, HOW COME IT IS 25? YOU HAVE TO BE INCOME TESTED VERY YEAR, AND FROM MY PERSPECTIVE AS A SINGLE PARENT, IT IS DIFFICULT, BUT YOU ARE GOING TO DO WHATEVER YOU CAN FOR YOUR CHILD. SOME FAMILIES ARE VERY STRESSED OUT, AND TO ADD THE BURDEN OF MEANS TESTING IS AWFUL. SOME FAMILIES CANNOT GET COMMUNICATION DEVICES THAT THEY NEED, ADDING EXTRA PRESSURE ON THE FAMILY ONCE AGAIN.

WE HAVE HAD TREMENDOUS SUPPORT FROM THEM.

I DO TAKE ISSUE WITH A COMMENT THAT WAS MADE TO ME, THAT A FATHER IS NOT A FAMILY MEMBER.

I WOULD LIKE NOT HAVING TO FIGHT FOR SERVICES AND SUPPORT SO MUCH, I WOULD LIKE TO SEE MORE CARE,

MORE RESPITE AND TRANSPORTATION SERVICES SO WE DO NOT HAVE TO WORRY. ALSO MORE THINGS FOR HER TO DO THROUGH THE SCHOOL YEAR SO SHE WILL NOT BE SO BORED.

I AM PLEASED THAT THEY HAVE ALLOWED PARENTS TO CHOOSE WHERE SERVICE OPTIONS ARE TO BE DONE. FREEDOM OF CHOICE IS WONDERFUL. WHAT I AM UNHAPPY ABOUT IS THE \$3,000 CEILING DOES NOT FIT WITH PEOPLE THAT HAVE MULTIPLE DISABILITIES. THE OTHER PART IS PARENTS ARE HAVING TO FIND THE CAREGIVERS, AND DO THE BOOKWORK, ETC. SOME PARENTS ARE NOT CAPABLE OF DOING THAT. THE LAST THING THEY NEED IS ANOTHER JOB ALONG WITH HAVING THE JOB OF A PARENT WITH A CHILD WITH MULTIPLE DISABILITIES. THE AGE 25 PROBLEM, PARENTAL CONTRIBUTION WITH DSP MUST BE PAID FOR BECAUSE HE LIVES WITH US! WE HAVE NO CHOICE!

WE HAVE THE BEST DSP WORKER WE COULD POSSIBLY HAVE. THE PROGRAM HAS GIVEN [] MANY VALUABLE EXPERIENCES. HE HAS DEFINITELY GAINED FROM THE PROGRAM SOCIALLY. I WOULD LIKE TO SEE BENEFIT FROM THESE SURVEYS, OVERALL.

BROCHURE OR PAMPHLETS TO EXPLAIN, RATHER THAN WORD OF MOUTH, OR WHAT THE WORKER THINKS IS APPROPRIATE.

I AM NOT PLEASED WITH THE DISCRIMINATION WITH THE AGE LIMITATIONS, SOME THINGS ARE NOT COVERED BY DISABILITY SUPPORT WHICH SHOULD BE COVERED.

I FIND THEY HAVE DONE A GOOD JOB OF MAKING IT AN INDIVIDUAL PLAN, RATHER THAN JUDGING THEM AS A GROUP.

THAT IS AVAILABLE TO US THROUGH DSP, AND WHAT IS ACCESSIBLE TO US, EXPENSE MONIES TO DO FUN THINGS, ARE THEY THERE FOR FAMILY THINGS?

MOST PEOPLE ARE TIRED AND BURNT OUT, AND THE DSP SHOULD BE UPFRONT WITH WHAT IS AVAILABLE, IT IS HARD BECAUSE THERE IS A MINIMUM AND MAXIMUM, AND YOU HAVE TO WORK WITH THE DISABLED PERSON BEFORE YOU KNOW WHAT THEY NEED. ONE PERSON MAY REQUIRE MORE WORK, BUT CAREGIVERS ARE PAID THE SAME FOR BOTH. WE SHOULD NOT HAVE TO "DIG" FOR INFORMATION, IT SHOULD BE THERE FOR THEM, THE DSP IS SUPPOSED TO BE THERE TO HELP PEOPLE, SO WHY NOT JUST LESSEN THE STRESS. TERMINOLOGY, RESPITE AND DAY SUPPORT ARE TWO DIFFERENT SUPPORTS AND MOST PEOPLE DO NOT KNOW THE DIFFERENCE. IT CONFUSES THEM.

A \$3000 CAP FOR HOME RENOVATIONS IS RIDICULOUS. IT WOULD COST THE GOVERNMENT A LOT MORE IF THEY HAD TO LOOK AFTER []. HIS EQUIPMENT WILL COST A LOT WHEN HE NEEDS A NEW ONE BUT THE PROGRAM JUST OFFERS A ONCE IN A LIFE TIME PURCHASE FOR THE EQUIPMENT. I CANNOT AFFORD IT. I DO NOT WANT []'S QUALITY OF LIFE TO CHANGE OR SUFFER. WHAT URKS ME IS WHEN PEOPLE FROM THE DEPARTMENT PHONE AND ASK FOR HIM. THOSE PEOPLE HAVE JOBS, BUT THEY DO NOT KNOW WHO THEY ARE WORKING FOR. JUST THEY OTHER DAY IT HAPPENED. []S WORKER WOULD NEVER DO IT, BUT IT HAS HAPPENED A LOT.

IT HAS IMPROVED A LOT OVER THE YEARS. THEY ARE VERY GOOD, I JUST HAVE TO PHONE, THEY HAVE HELPED A LOT OVER THE TRANSITION.

DSP WILL NOT COVER BOTH THE DAY PROGRAM AND SUMMER VACATION.

TRYING TO GET RECEIPTS FOR EVERYTHING THE MONEY IS BEING USED FOR, AND PARENTS THAT ARE LOOKING AFTER THE DISABLED PERSON AND DOING THE THINGS THAT WOULD CONSTITUTE A DAY PROGRAM SHOULD BE COMPENSATED OR PAID FOR THAT KIND OF THING.

I AM NOT SURE THAT THE SCREENING TOOL THEY USE TO EVALUATE THE NEEDS/DISABILITY CAPTURES THE EXTENT OF THE DISABILITY OR THE COMPLEXITY FINANCIALLY AND OTHERWISE. THEY NEED TO SUPPORT MORE OF A FAIR AMOUNT OF AWARENESS. THERE ARE WORKSHOPS AVAILABLE BUT ARE APPROXIMATELY \$400, BUT IT IS NOT AN OPTION TO HAVE THE DSP PAY FOR IT. THEY SHOULD REALIZE THAT A DISABLED PERSONS NEEDS ARE BEST MEANT BY HAVING THE PARENTS/CAREGIVERS TOTALLY AWARE OF ALL THAT IS OUT THERE FOR THEM AND TO BE EDUCATED, BUT THE DSP DOES NOT SUPPORT THIS. I AM GLAD FOR THE HELP THEY HAVE GIVEN ME.

MORE PERSONAL CONTACT BETWEEN DSP/CAREGIVERS/PARENTS AS TO WHAT IS AVAILABLE. WHAT IS COVERED, AND THEY DO NOT PROVIDE US WITH ENOUGH INFORMATION.

I WISH HE COULD HAVE JUST A LITTLE BIT MORE MONEY, \$400 A MONTH IS NOT MUCH IN THIS DAY AND AGE. FOR HIM TO GET BY ON.

I AM NOT SURE WHY PEOPLES INCOME ARE LOOKED AT, DSP SHOULD BE NEEDS BASED AND THAT AGE IS

DISCRIMINATED UPON BASED ON WHETHER THEY ARE 25 OR OLDER OR NOT.

AT THE MOMENT, [] HAS HER MOTHER AND HER FAMILY. HOWEVER, HER MOTHER IS VERY OLD AND I DO NOT THINK THE SISTERS WILL TAKE HER AS MUCH AS HER MOTHER HAS, AND THEN THERE WILL BE THE ISSUE OF RESPITE CARE.

DSP HAS APPROVED THE SUPPORTS [] NEEDS FOR HER WEIGHT REDUCTION PLAN. BUT [] HAS NOT BEEN SO GOOD AT IMPLEMENTING. IF THINGS DO NOT HAPPEN SOON, SHE WILL LET THE DSP KNOW, BUT SHE HAS NO COMPLAINT WITH THEM.

I THINK IT IS IMPORTANT THAT THE PROGRAM PROVIDE FOR PERSONS WHO ARE SENIORS AND THAT THEY RECOGNIZE THE NEEDS OF THOSE PERSONS WHO ARE MENTALLY CHALLENGED BUT GETTING OLDER THEMSELVES.

THE DSP WORKER CAME OUT TO THE HOUSE TO TALK TO THE GIRLS AND SHE WAS GREAT. SHE TALKED TO THEM ALL INDIVIDUALLY ABOUT THEIR LIFE AND THEN STAYED FOR SUPPORT WITH THEM. THEY HAVE BEEN REALLY GREAT WHENEVER I HAD A QUESTION FOR THEM.

THE COMMUNICATIONS BETWEEN THE WORKER AND THE PARENTS NEEDS TO BE IMPROVED. COMMUNITY RESOURCES SHOULD BE INCLUDES AND PARENTS SHOULD BE MADE AWARE OFF THE WORKSHOPS AND LECTURES THAT TAKE PLACE. IF YOU HAVE A CRISIS THE WORKER SHOULD DEFINITELY HELP MORE.

I DO NOT WANT THEIR MONEY..I WANT PROGRAMS AND SERVICES. YOU TALK ABOUT THE DSP LIKE I TALK TO THEM ALL THE TIME- THEY DO NOT CONTACT ME- THERE IS NO COMMUNICATION THERE- THEY ONLY CALL TO RE-ASSESS. THEY SAY THAT IT IS GEARED TOWARDS YOU, BUT IT IS NOT. I GOT A WORKER THROUGH PRIMARY CARE CONSULTING. A ONE ON ONE WORKER FOR [], IT IS GOING SO WELL. THERE IS COMMUNICATION AND SHE UNDERSTANDS/SHE IS SOMEONE THAT [] CAN CONNECT WITH AND TALK WITH. SHE HAS MADE A HUGE DIFFERENCE.

I THINK THE BIGGEST THING, FOR MY SON TO FEEL SAFE IN HIS HOME, THAT A WORKER IS NOT GOING TO HURT HIM. THAT HE HAS BEEN AFRAID OF THE LAST DISABILITY SUPPORT WORKER, AND THEY WILL NOT GIVE ME A NEW ONE.

RESIGNED TO THE FACT THAT WE HAVE TO PAY FOR WHATEVER SHE NEEDS, THE LITTLE CHEQUE SHE GETS GOES IN THE BANK, FOR A LOT OF FAMILIES IT IS REALLY HURTING THEM, THERE IS NOT SUFFICIENT MONIES.

I THINK THAT THEY SHOULD BE ABLE TO GO TO ANY PROGRAM THAT THEIR CAREGIVER CHOOSES THEM TO GO AND THEY SHOULD BE FUNDED FOR IT. I THINK THAT THEY WENT INTO THE DSP TOO FAST AND DID NOT LISTEN TO ANYBODY IN THE PROCESS. SUPPORT SHOULD BE AVAILABLE, SOME PEOPLE HAVE ACCESS TO IT, AND OTHERS DO NOT, THE WHOLE SCREENING PROCESS SHOULD BE BETTER. THEY HAVE [] WAY UP ON THE LIST THEN SHE ACTUALLY IS AND THEY THINK THAT SHE IS BETTER OFF THAN SHE ACTUALLY IS. EVERYBODY NO MATTER WHAT SHOULD GO TO A PROGRAM THAT WOULD BE MORE BENEFICIAL IN THE LONG RUN. IT IS COMMON SENSE.

I THINK THEY SHOULD HAVE MORE MONEY FOR CLOTHES AND MORE PLANNED ACTIVITIES, ENTERTAINMENT.

THERE SHOULD BE MORE MONEY ALLOTTED TO THE PROGRAM. I AM HAPPY WITH WHAT SHE IS RECEIVING (ANY BIT HELPS) BUT I AM VERY UNHAPPY WITH WHAT THEY TAKE OFF BECAUSE OF WHAT WE MAKE. I DO NOT APPRECIATE BEING PENALIZED BECAUSE OF WHAT MY HUSBAND AND I MAKE. IF WE DID NOT HAVE IT, HER QUALITY OF LIFE WOULD SUFFER.

THE FACT THAT THE CONTRIBUTION IS SO HIGH FROM THE PARENTS.

IT IS VERY DISCRIMINATORY BASED ON AGE AND SOCIAL STATUS, PARENTAL INCOME SHOULD HAVE NOTHING TO DO WITH THE SUPPORTS AND SERVICES THAT ARE AVAILABLE TO MY DAUGHTER. I THINK THE MINISTER SHOULD REVISIT THE DSP PROGRAM AND MAKE IT SO THAT THE PROGRAM IS NOT DISCRIMINATING TOWARDS AGE, OR WHERE A PERSON LIVES. I THINK THAT MR. BALLUM SHOULD ADDRESS THIS SITUATION IMMEDIATELY. I HAVE FILED A COMPLAINT WITH THE HUMAN RIGHTS COMMISSION.

I HAVE A HARD TIME SEEING WHY THE AGE GROUPS 18-25 DO NOT RECEIVE DISABILITY SUPPORT.

PEOPLE WITH DISABILITIES WHO REACH 18 YEARS OF AGE ARE NOT CONSIDERED ADULTS AND THIS HURTS THEIR SUPPORTS AND SERVICES. THERE ARE DIFFERENT ONE ON ONE SUPPORTS WAGES BASED ON REGION, WHICH I DO NOT LIKE. I ALSO HAVE MIXED FEELINGS ON THE "MEANS" TESTING.

THE TRANSPORTATION FUNDING IS MINIMAL, MAKING IT DIFFICULT, THE MAXIMUM RATE OF PAY FOR SUPPORT PERSONS IS \$10/HR AND IN SOME REGIONS THAT IS BEING ADHERED TO AND SOME IT IS NOT, AND THAT CAUSES

DISPARITY AMONG THE REGIONS AS SOME GET PAID UP TO \$15/HR. THERE NEEDS TO BE AN INVESTMENT IN RESIDENTIAL FACILITIES.

I THINK THEY SHOULD GIVE MORE SUPPORT FINANCIALLY SO THESE PEOPLE CAN SOCIALIZE OUT IN THE COMMUNITY, OUT IN PUBLIC. I DO NOT THINK THAT THEY GET ENOUGH. WE OWN OUR OWN BUSINESS AND I HAVE TO BE THERE ALL DAY AND I NEED A SITTER FOR [] WHO WOULD TEACH HER SKILLS AND SUCH.

IT WOULD BE NICE TO GET SOME MORE FINANCIAL SUPPORT FOR SPEECH THERAPY.

THERE IS NOT ENOUGH RESPITE CARE.

I THINK WHEN YOU MAKE APPOINTMENTS FOR THEM (SAY FOR HIS EYES) THEN YOU HAVE TO CALL D.S.P. AND GIVE THEM THE DATE OF THE APPOINTMENT. THIS IS NEW.

YOU SHOULD NOT HAVE TO GO TO AN APPEAL BOARD. THE DSP WORKERS THAT HAVE ALREADY REFUSED YOU AND THEN THEY ARE THE ONES ON THE BOARD OF APPEALS. THAT IS AN UNFAIR PRACTICE RIGHT OFF THE BAT.

THAT PARENTS ARE BEING "PUT ON". HE IS A SEVERELY BRAIN DAMAGED 40 YEAR OLD ADULT. IF HE WERE PLACED IN A GROUP HOME, ALL HIS EXPENSES WOULD BE PAID FOR BY THE GOVERNMENT - MEDICINE, SPECIAL EQUIPMENT, CLOTHING, EVERYTHING. BUT BECAUSE HE IS AT HOME WITH US, WE HAVE TO PAY FOR SO MANY THINGS (TREADMILL, ETC.) THAT ARE NOT COVERED BY THE GOVERNMENT, AND WHEN YOU ARE ON A FIXED INCOME IT IS HARD. RESPITE CARE MONEY IS NOT ENOUGH EITHER.

THIS IS ALL RELATIVELY NEW TO ME AND HE IS VERY HAPPY AND EVERYTHING IS RUNNING VERY SMOOTH.

IT IS DIFFICULT TO UNDERSTAND AND SEE WHY THE LEVELS OF FINANCIAL AID IS WHAT IT IS.

I AM VERY HAPPY THAT I DO NOT HAVE TO WORRY, I DO NOT HAVE A PILE OF MONEY OR ANYTHING, BUT WHEN [] NEEDS TO GO TO THE HALIFAX HOSPITAL, I DO NOT HAVE TO WORRY, OUR WORKER ARRANGES FOR US TO STAY AT THE RONALD MCDONALD HOUSE, AND HELPS US WITH IT. I FIND HER VERY UNDERSTANDING AND HELPFUL. IT IS PLEASURE HAVING HER FOR A WORKER. SHE IS THE TYPE OF WORKER, I CAN SIT DOWN AND TELL HER ANYTHING. MANY TIMES I TALK ABOUT MYSELF, SHE IS EASY TO TALK TO.

I THINK THAT IT IS NOT BEING FULLY EXPLAINED WHAT TYPES OF SUPPORTS AND SERVICES THAT ARE COVERED. THERE MAY BE A PROBLEM THAT I MAY NOT THINK OF, AND SOMETHING THAT WOULD BE OF HELP TO [] WILL NOT RECEIVED BECAUSE WE DID NOT KNOW THAT SUPPORT OR SERVICE WAS AVAILABLE FOR HIM. SOME MORE INFORMATION ABOUT THE SUPPORTS AND SERVICES WOULD BE VERY HELPFUL.

SHE IS AN ADULT 19 - SHE IS LEFT OUT ON A LIMB, IT IS UNFAIR TO HER AND HER PARENTS. THEY TAKE OUR INCOME INTO CONSIDERATION. WE SOLD OUR FARM AND BECAUSE OF THAT, WE ALMOST LOST ALL OUR SUPPORT AND SERVICES FOR [], BECAUSE IT INCREASED OUR NET INCOME. THE MONEY FROM THE SALE OF OUR FARM WENT TO PAY OFF BILLS, SO WE DID NOT GAIN FINANCIALLY, WE LOST OUR LAND, OUR MEANS OF MAKING AN INCOME. AND WE HAD TO FIGHT TO KEEP SUPPORTS AND SERVICES FOR [].

THIS NEW PROGRAM IS BETTER FOR THE CLIENTS BECAUSE THEY SEEM TO HAVE MORE MONEY TO GO AND DO THINGS. WITH THEIR OLD MONTHLY ALLOWANCE IT MIGHT HAVE GIVEN THEM ENOUGH FOR A MOVIE. NOW THEY HAVE MONEY TO ENJOY THEIR LIVES AND THEY CAN AFFORD A LOT MORE SOCIAL ACTIVITIES ON THE WEEKENDS.

KIDS WITH DISABILITIES NEED MORE MEDICAL HELP THAN REGULAR KIDS AND I AM CONCERNED THAT THEY WILL NOT SUPPORT ME BECAUSE IT WAS SUCH A BIG PROBLEM THE LAST TIME WHEN SHE HAD SURGERY ON HER HEART. I OFTEN GET CONCERNED BECAUSE I AM NOT SURE IF HER MEDICAL NEEDS WILL BE TAKEN CARE OF AND THIS PROGRAM SHOULD SUPPORT THAT AFTER ALL ITS THE MOST IMPORTANT THING. IF THEY DO NOT HAVE THEIR HEALTH WHAT DO THEY HAVE?

IF SHE WERE LIVING ON HER OWN, IT WOULD NOT BE ENOUGH. WE ARE ON A FIXED INCOME, AND MY BILLS HAVE TO COME FIRST. MONEY PROBLEMS BECAUSE WE CANNOT AFFORD TO DO THINGS THAT SHE WANTS TO DO.

I THINK THE MONEY IS ACCEPTABLE- I JUST TAKE WHAT THEY GIVE ME. I GUESS THAT I COULD ALWAYS GET MORE!

IF ANYTHING SHOULD HAPPEN TO ME, I AM WONDERING WHO WILL LOOK AFTER HER AND WHO WILL CARE FOR HER AND HOW THAT WILL BE DONE.

I DO NOT THINK A FAMILY SHOULD HAVE TO PAY A PERCENTAGE, IT EFFECTS QUALITY OF LIFE. I HAVE TO ASK FOR EXTRAS THAT SHE NEEDS, IT SHOULD BE INCLUDED IN WITH THE MONIES I GET, I SHOULD NOT HAVE TO APPLY FOR

EACH THING THAT SHE NEEDS, EACH AND EVERY TIME SHE NEEDS SOMETHING. THEY SHOULD ASK MORE QUESTIONS ON THEIR YEARLY PLANNING PROGRAM SHEETS. THE RIGHT QUESTIONS ARE NOT ASKED, SO EVERY TIME I NEED SOMETHING I HAVE TO APPLY FOR IT, WHEN IT COMES UP DURING THE YEAR.

AT PRESENT HIS DISABILITY SUPPORT IS DEPENDENT ON WHAT WE MAKE. [] CANNOT HAVE A CAR AND WE HAVE TO DRIVE HIM EVERYWHERE. WE ARE TRYING TO SUPPORT HIM THROUGH UNIVERSITY, HOPEFULLY IT WILL HELP HIM FIND A REAL JOB. IF HE CANNOT, HE WILL HAVE TO BE HOME AND IT IS NOT FAIR THAT THEY TAKE OUR WAGES INTO ACCOUNT BECAUSE WE CHOOSE TO GIVE HIM A HOME. HE WOULD NOT BE IN UNIVERSITY WITHOUT THE PROGRAM, BUT THERE ARE SO MANY THINGS THAT ARE IMPORTANT TO [] THAT WE HAVE TO SUBSIDIZE THAT MAKE HIS LIFE BETTER, WORKING WITH A HOCKEY TEAM, ALL THE THINGS THAT ARE FUN LIKE THE SPECIAL OLYMPICS.

THERE ARE NOT ENOUGH PEOPLE TO DO THINGS WITH PEOPLE WITH DISABILITIES SO THAT THEY HAVE ENOUGH TO DO IN THEIR FREE TIME.

I THINK SHE ONLY GETS SO MUCH, AND OUT OF THAT IF WE WANT TO HAVE A WEEKEND AWAY, THEN I HAVE TO PAY THE PEOPLE TO LOOK AFTER HER (RESPIRE). THEN THERE IS NOT TOO MUCH LEFT FOR CLOTHES OR SOMETHING ELSE SHE NEEDS.

SOMETIMES I WISH THAT THERE WERE MORE PEOPLE WITH MORE IDEAS FOR THINGS FOR [] TO DO FOR ACTIVITIES.

I THINK THEY SHOULD BE WORKING MORE WITH HER AND HELP HER MORE.

WHAT THEY OFFER IS GOOD BUT THERE SHOULD DEFINITELY BE MORE OUT THERE FOR THE CHILDREN WITH SPECIAL NEEDS AND THEIR PARENTS.

THEY DO NOT SIT DOWN AND TELL YOU WHAT IS AVAILABLE, IT SEEMS LIKE IT IS ALL HIDDEN.

IT WOULD BE NICE TO KNOW WHO THE DSP WORKER IS, AND TO PUSH AND GET HIM INVOLVED IN MORE THINGS, IF YOU DO NOT KNOW WHAT THE SERVICES ARE, YOU CANNOT USE THEM

IT SHOULD NOT BE BASED ON FAMILY INCOME. THE DSP SHOULD HAVE MORE RESOURCES FOR PROVIDING CERTAIN PROGRAMS, LIKE RESPIRE CARE, COMMUNITY OUTINGS, PROGRAMS LIKE THAT.

IT IS BASED ON MY INCOME, SO I STILL HAVE TO PAY A HUGE CHUNK FOR HIS CARE.

IT IS A GREAT HELP TO FAMILIES WITH THIS PROBLEM, IT CAN BE A FINANCIAL DRAIN ON THEM.

WE ARE JUST PLEASE TO BE ABLE TO GET WHAT WE GOT SO FAR.

I DO NOT THINK THEY ARE GEARING IT TO PROVIDE CHILDREN WITH SPECIAL NEEDS THE THINGS THAT THEY NEED. I THINK THAT THE DSP IS MORE GEARED TOWARD LOW INCOME FAMILIES.

I THINK THE WHOLE IDEA IS FANTASTIC

I THINK THAT FAMILY MEMBERS SHOULD GET SUPPORT THE SAME WAY THAT CAREGIVERS GET SUPPORT FOR LOOKING AFTER SOMEONE WITH A DISABILITY.

TRAVEL ALLOWANCE IS NO LONGER AVAILABLE- I AM JUST GETTING BACK FROM HALIFAX- 8 TIMES SO FAR THIS YEAR, NO HELP AVAILABLE. SHE WAS THERE TO SEE A DR. TRANSPORTATION FOR [] TO GET FROM POINT A TO POINT B FOR SOCIAL ACTIVITIES IS NOT COVERED. I MISS A LOT OF TIME FROM WORK TO DO IT. THE APPEAL HEARING PROCESS IS VERY JUDGMENTAL AND BIASED. DISABILITY SUPPORT PERSONNEL REALLY NEED TO KNOW APPROPRIATE AND PROPER PROCEDURES. DSP WORKER NEEDS TO BE MORE OPEN REGARDING SUPPORTS THAT COULD OR CAN BE AVAILABLE. MORE DOLLARS ALLOTTED FOR IBI START-UP. INCREASED DOLLARS ALLOWED FOR THERAPISTS.

I WOULD LOVE TO HAVE A RESPIRE CARE WORKER STAY FOR LONGER THAN THREE HOURS ON TUESDAYS AND THURSDAYS SO THAT I COULD HAVE SOME FREE TIME.

I BELIEVE THAT THE LEVEL OF SUPPORT AND CARING THAT WE RECEIVE FROM OUR SOCIAL WORKER HAS BEEN TERRIFIC. BUT I WOULD LIKE TO SEE SOME MORE THINGS HAPPEN: PEOPLE SHOULD BE MADE AWARE THAT THERE IS HELP OUT THERE. [] WAS DIAGNOSED AT 13 MONTHS, WE STRUGGLED UNTIL SHE WAS 8 YEARS OLD WHEN WE FIRST FOUND OUT THAT SUPPORTS WAS AVAILABLE. DOCTORS DID NOT EVEN KNOW ABOUT THIS, DOCTORS SHOULD KNOW AND SHOULD SHOW THE PARENTS WHAT IS AVAILABLE FOR THAT CHILD. 2) EVERY YEAR NEW MEDS

ARE APPROVED YET WE CANNOT GET ANY COVERAGE FOR THEM. DSP WILL NOT PROVIDE COVERAGE FOR THE NEW MEDS, ONLY OLD MEDS.

I DO NOT FEEL THAT A PERSON IS DEPENDENT ON THEIR PARENTS AT 25 YEARS OLD.

THE PROGRAM HAS SERIOUS PROBLEMS, THE FIM HAS TO GO, IT IS UNFAIR, THE FACT THAT [] WILL BE DEPENDENT UNTIL 25 IS LUDICROUS AND DISCRIMINATING, THE FACT THAT I AM MEANS TESTED IS UNFAIR, THE FACT THAT IF MY HUSBAND AND I DIE TOMORROW, AND MY SON HAD TO TAKE OVER CARE THAT WOULD BE MEANS TESTED, IS HORRIBLE TOO, THERE ARE TOO MANY PROBLEMS, HAVING TO APPEAL TO A BOARD OF DSP PEOPLE, AT LEAST ONE INDEPENDENT MEMBER HAS TO BE THERE, IT IS TERRIBLY INTIMIDATING, TO APPEAL TO THE PEOPLE THAT TURNED YOU DOWN. I DO NOT THINK MY DS WORKER UNDERSTANDS AUTISM

NOT ENOUGH RESPIRE CARE, NOT KNOWING WHAT SUPPORTS AND SERVICES ARE AVAILABLE AND NOT BEING TOLD ABOUT IT.

WE HAVE BEEN SO LUCKY WITH OUR WORKER, SHE WILL REALLY WORK FOR US. I REALLY THINK THERE SHOULD BE MORE FUNDING, I FEEL AN ASSESSMENT SHOULD BE DONE, THEN THE PARENTS GIVEN THE MONEY TO MANAGE, AND DSP COULD CHECK TO SEE IF THINGS ARE GOING RIGHT, BUT THIS HAVING TO KEEP TRACK OF ALL THE RECEIPTS AND DOING ALL THE PAPER WORK IS HARD, ANY OTHER PERSON IS CONSIDERED AN ADULT AT AGE 18, BUT THE PEOPLE ON THE PROGRAM ARE NOT CONSIDERED ADULTS UNTIL THEY TURN 25, ALSO, THEIR PARENT'S INCOME IS LOOKED AT AND I DO NOT THINK THAT IS RIGHT.

MY ONLY SUGGESTION, IT COMES DOWN TO DOLLARS AND CENTS: A GUIDANCE COUNCILLOR OR PERSON LIKE A BIG BROTHER/MENTOR WHO COULD TAKE HIM UNDER HIS WING, HE DOES GET FRUSTRATED SOMETIMES. I WOULD LIKE TO SEE SOMEBODY HE CAN SIT DOWN & TALK MAN TO MAN WITH, BESIDES HIS DAD. HE GAINS A LOT FROM HIS SUPERVISORS THOUGH, THE MAN AT TREMPLOY HAS BEEN A GOOD INFLUENCE. A PAID CAREGIVER, SOMEONE WHO COULD TAKE HIM TO HOCKEY GAMES, OR OTHER ACTIVITIES, A BUDDY/FRIEND TO SOCIALIZE WITH.

JUST THAT IT HAS MADE A BIG DIFFERENCE IN [] LIFE. IT MADE IT POSSIBLE FOR ME TO GET A JOB. I CAN HIRE SOMEONE TO COME IN AND HELP [] OUT IN THE MORNING, SO NOW I DO NOT HAVE TO BE THERE AND I CAN WORK.

SOME OF THE DRUGS THAT WOULD HELP HIS VERY HIGH CHOLESTEROL ARE NOT COVERED SO HE HAS TO TAKE OTHER MEDICATIONS THAT ARE NOT AS GOOD, I WOULD LIKE THE BETTER DRUGS TO BE COVERED. I AM HAPPY THAT I AM RECEIVING SOME MONEY TO HELP OUT HIS FOOD AND STUFF LIKE THAT.

THEY DO NOT COVER DENTAL AND MEDICAL EXPENSES AND TRAVELLING EXPENSES LIKE THEY DO IN ONTARIO, AND YOU HAVE TO CLAIM THE MONEY YOU RECEIVE AS AN INCOME, WHICH YOU DO NOT HAVE TO DO IN ONTARIO EITHER.

I THINK THERE SHOULD BE FUNDING FOR THINGS LIKE SOCIALIZATION AND INTERACTION FOR KIDS. SOCIALIZATION IS THE BIG WALL WITH AUTISTIC KIDS AND THERE SHOULD BE MORE FUNDING THERE SO THEY CAN INTERACT WITH OTHERS AND EVENTUALLY BREAK THE WALL DOWN.

I THINK THERE SHOULD BE MORE FINANCIAL AID AND IT SHOULD NOT BE AS DIFFICULT TO GET AS IT IS AND SHOULD NOT BE ANY FIGHTING ABOUT TRYING TO GET THE MONEY EITHER.

EVERYONE IS NOT TREATED EQUALLY & YOU DO NOT GET ANSWERS TO YOUR QUESTIONS. I DO NOT THINK THEY SPEND THEIR MONEY WISELY BECAUSE THEY ARE SPENDING A FORTUNE ON GETTING THIS OFF THE GROUND AND THE QCRS WAS GREAT, IF IT IS NOT BROKEN, WHY FIX IT? I DO NOT UNDERSTAND WHERE THE IMPROVEMENTS ARE. [] WORKER HAS CHANGED & SHE DOES NOT EVEN KNOW HIM. I TRIED PHONING NUMEROUS TIMES, MY CALL IS NEVER RETURNED. SHE WAS SUPPOSED TO GET BACK TO ME ABOUT [] TEETH, BUT NEVER DID. I CANNOT SAY THIS OR DO THAT BECAUSE I AM PUPPET, I NEVER GET TO TALK TO THE PUPPET MASTER. WHAT IF [] NEEDED SOMETHING

I DO NOT THINK THE PROGRAM SHOULD BE INCOME BASED. WE ALL HAVE CHILDREN, AND CHILDREN WITH EXCEPTIONAL ABILITIES/DISABILITIES COST MORE MONEY. I DO NOT THINK THE GOVERNMENT SHOULD TAKE THE BRUNT OF IT (FINANCIALLY) BUT THEY SHOULD HELP OUT AND THERE SHOULD BE SUPPORT SOME PLACE, I HAVE YET TO SEE THEM. WE ARE AT THE TIME IN OUR LIVES NOW WHERE WE SHOULD BE PUTTING AWAY MONEY FOR OUR RETIREMENT BUT WITH WHAT MONEY? THERE IS NO EXTRA AROUND BECAUSE WE HAVE 5 GIRLS ALL WHO ARE IN AND OUT OF UNIVERSITY(SOME HAVE GRADUATED BUT HAVE HUGE LOANS TO PAY) AND IT JUST GETS TOUGH.

IT IS AN AWESOME PROGRAM, THE POTENTIAL IS THERE. I AM VERY CONCERNED WITH THE LIMITATIONS. WHEN SHE WAS RECEIVING THE \$60 FROM DSP IT WAS VERY BENEFICIAL TO HER, SUPERVISION TO TAKE HER TO SOCIAL EVENTS. NOW SHE GETS NOTHING WHATSOEVER, NOT ONE NICKLE. SHE HAS NO FAMILY IN PEI, SO SHE HAS

NOTHING. THE SUPERVISOR AT DSP, [], I FEEL [] IS NOT CLIENT FOCUSED, [] IS PROGRAM FOCUSED. I FEEL STRONGLY THAT [] DOES NOT TRY TO WORK WITH THE CLIENT, [] IS TOO CONCERNED WITH THE DOLLARS AND CENTS OF IT. WE HAVE TO DO A SECOND APPEAL FOR HER TO JUST GET SOME SPENDING MONEY.

FUNDING FOR THINGS LIKE EDUCATIONAL PROGRAMS, COMPUTER PROGRAMS SHOULD BE AVAILABLE. SUPPORT GROUPS FOR EVERYBODY SHOULD BE AVAILABLE. IF YOU CANNOT GET LITERATURE FROM THE PROGRAM THAN HOW DO YOU KNOW WHAT IS AVAILABLE? MATERIAL ON WHAT IS AVAILABLE FOR SUPPORT WOULD HELP THE MOST. I SUPPOSE JUST MORE WRITTEN COMMUNICATION FROM THE PROGRAM SENT TO THE PARENTS TO TELL US WHAT IS GOING ON WOULD HELP THE MOST.

IF THE MOTHER IS THE MAIN CAREGIVER, AND ENDS UP IN THE HOSPITAL AND THE HUSBAND HAS TO TAKE TIME OFF OF WORK TO TAKE CARE OF THE HANDICAPPED CHILD, THERE SHOULD BE SOME REIMBURSEMENT FOR THE TIME OFF OF WORK THAT THE HUSBAND HAD TO TAKE. IT MAKES IT HARD WHEN THERE IS ONLY ONE PERSONS INCOME COMING IN. AND WHEN THEY HAVE TO TAKE TIME OFF OF WORK IT MAKES THINGS HARD.

WHENEVER THEY ARE EVALUATING A CHILD OR ADULT FOR THE AMOUNT OF CARE THAT THEY NEED, THEY ASK SOME QUESTIONS THAT ARE REALLY SILLY. IT IS VERY DEMEANING AND I KNOW THAT THERE ARE TOUGH QUESTIONS THAT THEY HAVE TO ASK, BUT I THINK THAT THEY SHOULD REVAMP IT. IT SHOULD BE MORE PER PERSON, NOT DESIGNED FOR 500 000 PEOPLE, BECAUSE IT IS VERY TIME CONCERNING AS A LOT OF QUESTION DO NOT HAVE TO ASKED TO EVERYBODY. WE ARE THANKFUL FOR WHAT WE HAVE BEEN RECEIVING AND HOPE THAT IT WILL GET EVEN BETTER IN THE FUTURE. IT IS MUCH MUCH BETTER THAN IT WAS.

THE SUPPORTS FOR PEOPLE LIKE [] WITH MORE NEEDS ARE INADEQUATE.

THERE ARE PEOPLE WHO REQUIRE MORE SUPPORT AND SERVICES THAN OTHERS. [] DOES NOT FUNCTION AS WELL AS OTHER PEOPLE, SHE CANNOT DO AS MUCH AS SHE WOULD LIKE TO BECAUSE OF HER DISABILITY.

IN A CASE WHERE THE PERSON WHO NEEDS SPECIALIZED CARE, YOU NED A LOT MORE CARE THAN WHAT IS BEING PROVIDED.

I THINK THAT SINCE SHE HAS MOVED OUT THE SUPPORT PROGRAM HAS BEEN BETTER FOR HER BECAUSE BEFORE THAT IT WAS BASED ON MY HUSBANDS INCOME EVEN THOUGH SHE WAS 18.

I WORRY ABOUT THE FUTURE WITH THE PROGRAM, WE TAKE GOOD CARE OF HIM, AND WE THINK THAT HE IS HAPPY, BUT SOMEDAY, WE MIGHT NOT BE ABLE TO AFFORD TO HELP HIM. FOR EXAMPLE, SOON, HE WILL NOT BE ABLE TO WALK UP THE STAIRS, THEN WHAT WILL HAPPEN? WE WOULD NOT WANT TO GIVE HIM UP.

THE ASSISTANCE THEY GIVE FOR TRAVEL REALLY DOES NOT BEGIN TO COVER THE COST OF TAKING [] TO HALIFAX. WE HAVE TO TAKE TIME OFF FROM WORK, WE USUALLY HAVE TO STAY OVERNIGHT, BUY MEALS WHICH ARE NOT COVERED. EVEN IF THEY EXPECT US TO MAKE A CONTRIBUTION, WHICH I UNDERSTAND, THEY SHOULD BE LOOKING AT THE WHOLE COST OF THIS TRIPS RATHER THAN JUST GAS AND THE FERRY.

I HAVE A PROBLEM WITH THE MEANS TESTING PORTION OF THE DSP AND THE AGE CATEGORY CAPS FOR DSP SERVICES AND THE AMOUNT THAT DSP CAN GIVE TO PEOPLE FOR CERTAIN SERVICES AND THE NEEDS HAVE TO BE FIT INTO CERTAIN CATEGORIES TO BE CONSIDERED A NEED.

THEY HAVE GREAT WORKERS IN THERE, THEY REALLY LOOK AFTER THE PEOPLE WITH DISABILITIES.

IT SHOULD NOT BE BASED ON PARENTS INCOME, I THINK THERE SHOULD BE A WIDER RANGE OF THINGS THAT ARE COVERED.

THERE SHOULD BE AN EPILEPTIC SOCIETY OR ORGANIZATION HERE. Q86A:THE LEVEL OF FINANCIAL ASSISTANCE IS SOMEWHAT ACCEPTABLE.

I THINK THAT THE MONEY FROM THE DSP IS BEING WASTED ON ADMINISTRATION AND NOT ON THE DISABLED PEOPLE.

HE DOES HIS JOB WELL AND WORKS HARD, TWO JOBS AND HE IS PENALIZED FOR TRYING TO GET AHEAD. THEY CUT HIS ROOM AND BOARD MONEY AND THAT DOES NOT MAKE SENSE TO US. HE IS GOING TO GO BOARD SOMEWHERE ELSE, BECAUSE WE ARE GETTING ELDERLY AND ARE RETIRED NOW, JUST IN CASE SOMETHING HAPPENS TO US HE WILL HAVE A PLACE. WHEN HE BOARDS THERE, HIS BOARD CHEQUE WILL NOT BE CUT, IT IS CUT BECAUSE HE LIVES AT HOME WITH US. IT DOES NOT SEEM FAIR, BUT, DSP HAVE BEEN WONDERFUL TO US, THE SUPPORT OVER THE YEARS.

GET RID OF THAT USER FEE, CLIENT CONTRIBUTION OR PERCENTAGE OF WHAT SERVICE OR GOOD THAT IS REQUIRED. LIFETIME COST LIMIT ON CERTAIN THINGS LIKE REPAIRS TO YOUR HOME, LIKE WHEELCHAIR RAMP AND SHE IS ONLY 19 YEARS OLD. SO WHAT DOES SHE DO WHEN SHE NEEDS A NEW WHEELCHAIR RAMP LATER ON IN HER LIFE? AGE LIMIT - IF 65 YEARS OR OLDER YOU CANNOT GET DSP EVEN IF THAT PERSON NEEDS A NEW \$10,000 WHEELCHAIR!

IF I DID NOT WORK AND HELP SUPPORT HIM, WE COULD NOT MAKE ENDS MEET. MEDICINE GALORE, 18 PILLS A DAY HE TAKES, AND MY INSURANCE PAYS 80% OF THAT.

PAID PROGRAMMING SCHEDULE NOT ADVISED IF IT IS A GO OR NOT.

NEEDS WINTER CLOTHING ALLOWANCE. NEEDS CARE GIVER TO TAKE HER ON OUTINGS, MOVIES, SHOPPING. ALSO NEEDS CAREGIVER TO STAY WITH HER WHEN FAMILY WANTS TO GO AWAY. ALLOW MORE FOR PERSONAL THINGS. THEY DO NOT TAKE INTO ACCOUNT THAT FAMILIES ARE UNPAID CARE GIVERS, I HAVE BILLS, AND I CANNOT WORK BECAUSE SHE CANNOT BE LEFT ALONE.

Appendix D:

QUESTION: IS THERE ANYTHING ABOUT THE DISABILITY SUPPORT PROGRAM AND ITS SUPPORTS AND SERVICES THAT YOU WOULD LIKE TO COMMENT ON?

TRAVEL EXPENSES - IF THEY COULD BE USED AS OUR INPUT TOWARDS THINGS, IF WE WERE ALLOWED OUR TRAVEL EXPENSES TO BE USED TOWARDS WHAT WE PUT INTO HELPING HER, THAT WOULD HELP.

INFORMATION ON WHAT IS AVAILABLE UNDER THE DSP IS NOT QUITE CLEAR TO ME.

IT ANNOYS ME TO NO END, ONCE IN YOUR LIFETIME FOR ASSISTANCE FOR SOME THINGS, THAT IS RIDICULOUS. THIS LIFT IS NOT GOING TO LAST ME 30 YEARS, IF I NEED ANOTHER, THEN WHAT?

I JUST HAVE A CONCERN THAT IF SOMETHING WERE TO HAPPEN DOWN THE ROAD TO US AND [] COULD NOT WORK, I JUST WAS WONDERING IF THERE WAS ANY FORM OF SUPPORT FOR HIM IF WE WERE NOT THERE TO HELP. I AM NOT SAYING THAT HE IS NOT GOING TO WORK, BECAUSE HE LOVES HELPING WITH THE [], BUT THAT IS ONLY 2 MONTHS A YEAR THAT HE DOES THAT, AND IF WE WERE NOT HERE I JUST WANT TO KNOW WHAT FORM OF SUPPORT IS THERE FOR HIM IF IT IS NECESSARY.

I WOULD LIKE TO KNOW MORE ABOUT IT, AND WHAT MORE I AM ENTITLED TO.

I WAS VERY SATISFIED WITH THE WORKER AND THE SUPPORT THAT I RECEIVED. THEY WERE VERY GREAT AND I HOPE THE PROGRAM KEEPS ON GOING AND KEEPS UP THE GOOD WORK. I HAD INSURANCE THROUGH WORK, BUT THEY ONLY COULD COVER AROUND 20% AND THE DSP CAME THROUGH WITH ANOTHER 40% FOR ME AND THAT WAS GREAT AND HELPED A LOT. IT DID NOT TAKE LONG EITHER. I WAS PLEASED WITH THAT.

I WAS VERY THANKFUL OF THIS PROGRAM AND THE HELP THEY DID GIVE ME. I AM A MOM WITH 2 GIRLS, ONE WITH A []. WE WERE VERY DISHEARTENED AND SHOCKED WHEN WE WERE DECLINED BECAUSE THE DSP WORKER SAID THAT I WOULD HAVE NO PROBLEM AT ALL GETTING SUPPORT. MY LITTLE GIRL CAN BARELY BREATHE AND IF THERE IS NO BREATH IN LIFE THERE IS NO LIFE. SHE TAKES OVER 500 PILLS A MONTH AND SPENDS A LOT OF TIME IN HOSPITAL. I DO NOT WANT TO SOUND DISRESPECTFUL TO OTHERS BUT A WHEEL CHAIR IS NOT GOING TO SAVE A LIFE, BUT BREATHING WILL. CHILDREN DIE FROM []. IS THAT NOT SERIOUS?

I THINK THEY SHOULD MAKE MORE PEOPLE AWARE OF THE PROGRAM. I WAS BECOMING FRUSTRATED BECAUSE I DID NOT THINK THERE WAS ANYTHING OUT THERE TO HELP THE AVERAGE PERSON TO AFFORD EXPENSIVE DEVICES. MY DOCTOR TOLD ME ABOUT IT, THERE COULD BE MANY PEOPLE OUT THERE THAT ARE NOT AWARE OF THE PROGRAM AT ALL.

IT WAS GREAT. THEY GAVE ME MORE THAN WHAT I EXPECTED. I DID NOT EXPECT TO GET THE MONETARY AMOUNT THAT I GOT.

THE LADY AT THE HEARING AID PLACE PUT ME IN TOUCH WITH DSP IN SUMMERSIDE, AND WITHIN 3 WEEKS I HAD THE CHEQUE AND THE HEARING AIDS.

THEY HAVE HELPED ME OUT SO MUCH WITH MEDICATIONS AND DRUGS, HOWEVER THEY SHOULD HAVE PROGRAMS FOR PEOPLE LIKE US TO HELP MEET MORE PEOPLE LIKE ME. MOST OF US ARE JUST SITTING IN OUR APARTMENTS ALONE AND WE DO NOT GET TO MEET MANY PEOPLE BECAUSE OF THIS. THEY HAVE OUR NAMES AND NUMBERS AND PROBLEMS AND I THINK THAT THEY SHOULD HELP US. IT IS HARD BEING ALONE ALL OF THE TIME AND I WISH THAT THEY COULD MAYBE DO SOMETHING.

I WOULD LIKE TO SEE MORE OPPORTUNITY FOR PEOPLE WITH EMOTIONAL DISABILITIES TO GET SUPPORTS FROM THE PROGRAM. THERE IS COMPUTER INTERACTIVE SOFTWARE THAT WOULD HELP ME THAT IS NOT COVERED. IT IS REALLY DIFFICULT TO TRY TO GO BACK AND FORTH BETWEEN PROGRAMS. WELFARE COVERS SOME OF MY MEDICATIONS, BUT THERE IS ONE THEY DO NOT AND THE DSP SAY THEY CANNOT HELP ME. I DO NOT QUALIFY FOR ONE-ON-ONE SUPPORT, SOMEONE TO HELP ME GET OUT OF THE HOUSE. MY DISABILITY IS INVISIBLE. IT SEEMS SOME PEOPLE GET A LOT OUT OF THE PROGRAM AND SOME GET NONE AND IT SEEMS MORE GEARED TO PHYSICAL DISABILITY.

I ACTUALLY DO NOT KNOW ENOUGH ABOUT IT. IF YOU ARE A LOW INCOME SINGLE PARENT, I DO NOT KNOW IF THERE IS ANYTHING AVAILABLE FOR YOU. MY PROGRAM WAS CONNECTED THROUGH HRDC, AND WHEN MY EI FINISHED, SO

DID MY DISABILITY SUPPORT. SO, AT THE END OF THE SUMMER, WHEN MY EI WAS FINISHED, I WAS LEFT TO EITHER FIND A JOB OR GO ON WELFARE. NO OTHER OPTIONS.

THEY ARE WONDERFUL- THEY CAME INTO MY SONS HOME AND WE TALKED ABOUT DIFFERENT THINGS AND THE SCOOTER THEY GAVE ME IS JUST GREAT, AND I NEEDED A WHEELCHAIR RAMP..I DO NOT KNOW IF THEY PROVIDED THE SCOOTER OR NOT, BUT IT HAS BEEN A BIG HELP TO ME.

THE ONLY PROBLEM WAS THAT ONCE I STARTED BACK TO WORK THE DISABILITY SUPPORT STOPPED WHICH I CANNOT UNDERSTAND BECAUSE I STILL HAVE A DISABILITY. OTHER THAN THAT THINGS WERE GREAT.

I PRAISED IT UP, AND TOLD FRIENDS AT WORK, OTHER PEOPLE WENT ONCE I GAVE THEM THE PHONE NUMBER.

I FOUND THE GIRL THAT I WENT TO WAS VERY HELPFUL. VERY RESPECTFUL, IT WAS THE FIRST TIME THAT I HAVE EVER HAD TO CONSIDER GOING WITH A DIFFERENT AID THAN MY INSURANCE, BUT THE AIDS WERE QUITE EXPENSIVE. VERY EASY TO TALK TO AND SHE SEEMED VERY KNOWLEDGEABLE, IT WAS A GREAT EXPERIENCE.

THE PROCESS IS VERY SPEEDY, PEOPLE WERE CONCERNED AND HELPFUL. I WAS VERY SURPRISED ON HOW SMOOTH THINGS WENT.

IT IS VERY HARD TO GET HELP FROM DSP, AND IT IS HARD TO FIND THE INFORMATION ON THE PROGRAM. THE AMOUNT OF TIME IT TAKES TO GET AN APPOINTMENT, PROCESS THE PAPERWORK, THEN FIND OUT IF YOU GET ALL OR PART OF WHAT YOU NEED. IT JUST TAKES WAY TOO LONG AND IT IS NEVER ENOUGH.

WE WERE VERY PLEASED TO GET THE HELP WITH THE HEARING AID, HE IS ON DISABILITY CPP, ON A FIXED INCOME. WE ARE THANKFUL FOR THE HELP WE GOT.

I THINK THE PROGRAM IS WONDERFUL.

THEY ARE DOING A GREAT JOB TO TRY TO HELP DISABLED KIDS. SHE DID NOT ACTUALLY DO ANY ACTIVITIES, THE WORKER OFFERED BUT [] HAS NOT GONE OUT WITH THE GROUP YET. SHE WORKS ONE DAY VOLUNTEER WORK AT THE CHILDREN'S DAY CARE AND SHE JUST LOVES DOING THAT.

IT WOULD BE BETTER FOR SURVEYS LIKE THIS, IF THEY SENT IT IN THE MAIL, I WOULD GLADLY FILL IT OUT AND SEND IT BACK. MY HEARING IS NOT VERY GOOD.

I AM REALLY THANKFUL FOR THE PROGRAM AND FOR THEM GIVING ME THE FINANCIAL ASSISTANCE TO OBTAIN THE HEARING AID THAT I NEEDED. I NEVER WOULD HAVE GOTTEN IT IF IT WAS NOT FOR THEM BECAUSE IT COST TOO MUCH MONEY. I AM THANKFUL FOR THE PROGRAM. MY AUDIOLOGIST SAID THAT THE PROGRAM MIGHT ONLY LAST A YEAR OR THAT IT MIGHT ONLY BE AVAILABLE FOR A CERTAIN AMOUNT OF TIME AND I AM GLAD THAT THEY HELPED ME GET MY HEARING AID.

I WAS SURPRISED THAT I WAS ELIGIBLE AND VERY HAPPY TO HAVE RECEIVED IT. I WOULD NOT HAVE BEEN AWARE OF THE PROGRAM IF THE AUDIOLOGIST HAD NOT BROUGHT IT TO MY ATTENTION.

THE LACK OF INFORMATION IS DISGRACEFUL. I DO NOT KNOW WHAT SHE IS ENTITLED TO. WHAT SERVICES ARE AVAILABLE, I HAVE NEVER RECEIVED ANY PAMPHLETS OR BROCHURES ON THE PROGRAM. IT HAS BEEN VERY DISAPPOINTING. THE SUPPORT WORKER DOES NOT CONTACT US AT ALL, SOMETIMES SHE TREATS US WITH RESPECT, SOMETIMES SHE DOES NOT, I DO NOT KNOW IF SHE IS BUSY OR WHAT. IT SEEMS LIKE ANY TIME THERE IS A GOVERNMENT INVOLVED, YOU HAVE TO BE VERY SPECIFIC ABOUT WHAT YOU ARE ASKING, OR YOU WILL NOT GET AN ANSWER.

THE REVIEW PROCESS IS SEVERELY FLAWED, IT IS NOT FAIR TO PUT THE PARENTS THROUGH THE PROCESS.

ONCE I FOUND THE PROGRAM EVERYTHING WAS GREAT. WE WERE CLOSE TO LOSING OUR HOUSE BECAUSE OF THE COST OF [] AND ALL THOSE TRIPS TO HALIFAX. MY BIG CONCERN IS THAT WHEN WE WENT TO SOCIAL SERVICES INITIALLY, THEY JUST SAID THEY COULD NOT HELP US, THEY DID NOT REFER ME TO THE DSP PROGRAM. IT WAS WHEN I CALLED [] THAT I GOT REFERRED TO DSP. THEY NEED TO BE SHARPER WITHIN THEIR OWN DEPARTMENT AND MAKE SURE PEOPLE GET REFERRED TO THE PROBLEM. THEY NEED TO INCREASE PEOPLE'S AWARENESS OF THE PROGRAM.

I DO NOT KNOW IF THE HEARING AID PROGRAM IS STILL GOING, BUT IT SHOULD BE, IT IS A REALLY IMPORTANT SERVICE.

I THINK IT IS A GREAT PROGRAM.

MY ONLY CONCERN IS THAT THEY SEND THEIR CHEQUES OUT IN THE MAIL INSTEAD OF DIRECTLY TO THE HEARING AID COMPANY. SOMEBODY COULD TAKE THAT MONEY AND BLOW IT ON BOOZE OR DRUGS OR EVEN LEGITIMATE SERVICES INSTEAD OF ON THE HEARING AID, AND TOO MUCH OF THAT WOULD HURT BOTH THE PERSON AND THE PROGRAM AND JEOPARDIZE IT FOR OTHER PEOPLE. NOTE: THE RESPONDENT SAID THE WORKER WENT OUT OF HER WAY TO GET HER INTO A HRDC PROGRAM THAT HELPED HER GET HER JOB. SHE HAD BEEN UNEMPLOYED BEFORE THAT.

MY DS WORKER WAS VERY PROFESSIONAL/THOROUGH/NICE/EMPATHETIC/HER NAME WAS [] AND SHE WENT BEYOND HER DUTIES AND DESERVES RECOGNITION. I HAVE NOTHING BUT PRAISE FOR THE PROGRAM. I HOPE THAT IT CONTINUES IN THE FUTURE. I WISH THE PROGRAM COULD INCLUDE SENIORS, I DO NOT KNOW IF MANY PEOPLE KNOW ABOUT/OR KNOW A LOT ABOUT THE PROGRAM. I HEAR SO MANY NEGATIVES ABOUT THE PROGRAM, BUT I THINK DSP IS EXCELLENT.

I WISH I COULD GET ON THE PROGRAM ON GOING, NOT FOR LARGE AMOUNTS, BUT JUST FOR THINGS LIKE BATTERIES FOR MY HEARING AID.

I WAS VERY IMPRESSED WITH BEING ABLE TO GET IN SO QUICK AND RECEIVE A QUICK ASSESSMENT AND FAST SERVICE.

THEY SHOULD HAVE A BETTER FOLLOW UP. I LEFT MESSAGES FOR MY WORKER AND I WENT IN A COMPLETE CIRCLE WHEN I WAS TRYING TO GET THINGS FOR []. I KEPT GETTING THE RUN AROUND. THEY GAVE ME DIFFERENT PEOPLE TO CONTACT OUTSIDE OF THE PROGRAM AND THOSE PEOPLE TOLD ME TO TALK TO THE DSP SO I WAS NO FARTHER AHEAD. [] WOULD BENEFIT FROM THE HELP I ASKED FOR AND IT WOULD HAVE HELPED HER BE MORE INDEPENDENT. HER QUALITY OF LIFE WOULD BE BETTER AND SHE WOULD BE SAFER. I THOUGHT THAT WAS THE PURPOSE OF THE PROGRAM.

THIS WAS GOOD, I WOULD BE INTERESTED TO KNOW WHAT SERVICES ARE AVAILABLE, BECAUSE I DO NOT KNOW.

I WAS VERY PLEASED TO GET THE GADGETS TO HELP ME OUT, THE FAT HANDLED KNIVES.(ETC). TO ME THE DSP IS VERY MISLEADING, IT DOES NOT DO WHAT IT PROMISES THAT IT WILL DO. IT IS JUST THAT I DO NEED A WALK IN SHOWER, BUT I CANNOT AFFORD THE RENOVATIONS TO PUT THE SHOWER IN. WHEN I WENT FOR THE INTERVIEW I WAS LED TO BELIEVE THAT WHATEVER MY NEEDS WERE, AS LONG AS THE DOCTOR AGREED, THE DSP WOULD HELP. I HAD THE OT COME TO MY HOUSE, SHE MADE ASSESSMENTS AND SAID THAT I DID NEED THE SHOWER, THE PAPERWORK WAS PASSED IN, BUT THE MONEY THAT I RECEIVED DID NOT INCLUDE RENOVATIONS.

I THINK THAT IT IS VERY GOOD PROGRAM.

I DID NOT KNOW ABOUT THE DSP UNTIL MY AUDIOLOGY SPECIALIST TOLD ME, I THINK THERE SHOULD BE MORE INFORMATION AVAILABLE TO PEOPLE WHO NEED IT.

I HAVE NOTHING BUT PRAISE FOR THE PROGRAM, I THINK IT IS GREAT.

IT WAS SO WONDERFUL BECAUSE THE HELP WAS THERE WHEN WE NEEDED IT. THERE IS REALLY NEVER ENOUGH MONEY GIVEN BY THE DSP.

OVERALL, I WAS VERY SATISFIED.

I WAS SURPRISED AT THE TIME THAT THE MONEY WAS OFFERED WITH NO REQUIREMENT FOR PROOF OF PURCHASE OF THE AIDS. I WAS QUITE IMPRESSED, IT CERTAINLY RESULTED IN MY STRESS LEVEL BEING QUICKLY LOWERED, AND IT CERTAINLY CONTRIBUTED TO ME BEING ABLE TO DO MY JOBS MORE EASILY AND COMFORTABLY. I WAS VERY IMPRESSED THAT THE PROVINCIAL GOVERNMENT WAS OFFERING SUCH A PROGRAM, I WAS REFERRED BY THE PERSON WHO DID THE TESTING, I WAS NOT AWARE OF IT BEFORE. IT IS MY OPINION THAT SOME KIND OF PROOF OF PURCHASE WOULD BE A REASONABLE REQUIREMENT, THAT WAS A SURPRISE, IT SHOULD NOT HAVE BEEN DONE LIKE THAT.

I AM HAPPY. I WOULD LOVE TO SEE THEM GET SOME FORM OF JOB MENTORING, SOME KIND OF TRAINING THAT HE COULD GO FOR, MAYBE WITH AN ALLOWANCE, ONCE HE IS OUT AND SEES WHAT HE IS CAPABLE OF, HE WILL BE BETTER OFF. WITH A GROUP OF PEOPLE THAT REALIZE THAT SOME PEOPLE ARE DIFFERENT, THINGS LIKE FILING, THAT DO NOT TAKE A LOT OF SKILL, THAT OTHERS FIND TIME CONSUMING.

I THINK IT IS A WONDERFUL PROGRAM, THE REASON I WENT IS BECAUSE MY HEARING DETERIORATED, AND THROUGH MY WORK I ONLY RECEIVE 500 EVERY FEW YEARS, AND I COULD NOT AFFORD TO GET THE TWO HEARING AIDS THAT I NEEDED, THE \$500 DOLLARS FROM MY PROGRAM AT WORK PAID SOME AND DSP PAID THE REST. THE PROGRAM IS HELPING PEOPLE LIKE YOU WOULD NOT BELIEVE, KEEP UP THE GOOD WORK.

NOTHING OTHER THAN I AM REALLY SATISFIED WITH THE HELP THAT I GOT FROM THEM.

I HAVE FOUND MYSELF IN AN ODD POSITION, I HAVE MEDICAL CARE WITH THE []. MY DOCTOR WROTE A PRESCRIPTION STATING THAT I NEEDED A SHOWER CHAIR AND GRABBING BARS FOR MY SHOWER BUT BECAUSE THEY ARE NOT ON THE LIST I AM NOT ELIGIBLE FOR THEM TO COVER IT FOR ME. I AM ON LONG TERM DISABILITY AND I HAVE GOTTEN A SHOWER CHAIR AND I DO NOT KNOW IF I WILL BE ABLE TO BE REIMBURSED FOR IT. I STILL DO NOT HAVE A GRAB RAIL THOUGH EVEN THOUGH IT IS NECESSARY.

MY DOCTOR SENT A LETTER TO THE SOCIAL SERVICES BECAUSE I NEED SUPPORT FOR NEW MEDICATIONS FOR MY BACK. I HAD A [] CONDUCTED AND IT SAID I HAD A LOW FRACTURE RATE HOWEVER IT WILL GET WORSE WHEN YOU HIT 65, BUT IT COULD HAPPEN FROM ANYTIME FROM HERE ON OUT. I AM 61 AND I CAN FIX IT NOW RATHER THAN WHEN IT GETS WORSE, HOWEVER I CANNOT AFFORD THE MEDICATION, I AM ON SOCIAL ASSISTANCE MYSELF AND IF I COULD BUY THE MEDICATIONS MYSELF I WOULD. THE LETTER WAS SENT OVER A YEAR AGO AND I HAVE NOT HEARD ANYTHING MORE ABOUT IT.

THE PROCESS TIME IS A LONG TIME TO WAIT, NOT A VERY LONG TIME, BUT LONG ENOUGH.

I AM REALLY HAPPY WITH THE PROGRAM. [], OUR WORKER WAS WONDERFUL. [] WAS SYMPATHETIC, UNDERSTANDING AND A GREAT HELP.

I DID NOT KNOW THAT IT EXISTED FOR PEOPLE LIKE ME, I DO NOT CONSIDER MYSELF DISABLED, I WEAR TWO HEARING AIDS. BUT, IT HELPED BECAUSE HEARING AIDS ARE SO EXPENSIVE. I WAS PLEASED TO BE CONSIDERED FOR THE PROGRAM. THE DS WORKER CAME TO MY HOME, BECAUSE I WAS ON CRUTCHES AT THE TIME, SHE EXPLAINED EVERYTHING TO ME, I THOUGHT THAT SHE DID A GREAT JOB. THEY WERE QUICK TO HELP. IT JUST NEEDS TO BE KNOWN THAT PEOPLE HAVE A SOURCE TO HELP THEM.

I THINK THEY WERE GREAT WITH ME. I HAD NO PROBLEMS WITH THEM AT ALL.

I AM 66, AND I STARTED THIS BEFORE I TURNED 65, SO WHEN THEY FINISH THIS LEG, I AM DONE. I DO NOT THINK THINGS SHOULD STOP AT 65, BECAUSE I WILL NEED THE LEG JUST AS MUCH AS SOMEONE YOUNGER THAN 65.

THE HEARING AIDS THAT THEY GAVE ME DO NOT WORK THAT WELL. I AM NOT HAPPY WITH THEM AT ALL. I AM GLAD THAT I DID NOT PAY THE \$2200 FOR THEM BECAUSE THEY DO NOT WORK. THE SUPPORT WORKER THAT I DEALT WITH WAS EXCELLENT, SHE IS A BUDDY OF MINE FROM [], AND EVERYTHING THAT SHE DID WAS GREAT.

I THOUGHT THE PEOPLE WERE WONDERFUL. THEY TOLD ME THAT IF I NEEDED ANYTHING ELSE TO COME IN AND SEE THEM. THEY WERE VERY NICE. [] SAID WHEN HE WAS OUT ON THE WATER HE SAW THE SEA GULLS BUT HE NEVER COULD HEAR THEM, NOW HE CAN.

THE SUPPORT WORKER WAS FANTASTIC.

THANK IT WAS ALL POSITIVE.

FOR THE SERVICE I RECEIVED (A HEARING AID) EVERYTHING WAS GREAT. I NEEDED THE HEARING AID FOR WORK, SO IT WAS VERY IMPORTANT.

IT APPEARS THAT HER AUDIOLOGIST THINKS THE PROGRAM IS FOR A LIMITED TIME. HER AUDIOLOGIST IS THE PERSON WHO TOLD HER ABOUT THE PROGRAM OTHERWISE, SHE NEVER WOULD HAVE KNOWN OR RECEIVED HELP FROM THE PROGRAM.

SHE THINKS THE TRANSPORTATION IS GREAT BUT SHE FEELS THERE COULD BE A LITTLE MORE.

THIS PERSON APPLIED FOR BENEFITS AND HAS NEVER BEEN CONTACTED. SHE INDICATED SEVERAL TIMES ABOUT HER DAUGHTER NOT BEING SAFE AROUND THE HOME BECAUSE OF HER BEING BLIND.

I CANNOT AFFORD TO DO THE RENOVATIONS MYSELF. WHEN IT FIRST CAME OUT (THE PROGRAM) I THOUGHT THAT IT WAS WONDERFUL, BUT IT JUST HAS NOT HELPED ME OUT LIKE I THOUGHT THAT IT WAS GOING TO. I KNOW SEVERAL PEOPLE THAT HAVE BEEN DISAPPOINTED BY THE DSP PROGRAM.

WE THOUGHT THAT IT WAS A GREAT PROGRAM.

Appendix E:

QUESTION: IS THERE ANYTHING ABOUT THE DISABILITY SUPPORT PROGRAM AND ITS SUPPORTS AND SERVICES THAT YOU WOULD LIKE TO COMMENT ON?

I DID NOT COMPLETE WRITTEN APPLICATION, JUST OVER THE PHONE. I DID NOT RECEIVED REPLY ONE WAY OR ANOTHER, WHERE I QUALIFIED OR NOT, I JUST NEVER HEARD ANYTHING WHAT SO EVER. I NEED WALKING SHOES AS I HAVE PROBLEMS WITH MY ANKLES AND MY LOWER BACK, I NEED BETTER SUPPORT THERE, ALSO A BED FOR GOOD SUPPORT AS I HAVE BACK PROBLEMS AND HAVE A LOT OF TROUBLE SLEEPING.

I THINK THAT THE SERVICE IS THERE WHEN YOU NEED IT, BUT IF YOU DO NOT REALLY QUALIFY FOR IT, IT IS THE CHILD THAT SUFFERS.

IT WAS EXPLAINED 1½ YEARS AFTER IT WAS CANCELLED. [] NEEDED GLASSES AND HEARING AIDS.

IT WAS GOOD, BUT THEN IT WAS CANCELLED.

[] SHOULD HAVE MORE SUPPORT SO THAT SHE CAN LIVE OKAY. MY HUSBAND AND I TAKE CARE OF HER AND NOW SHE IS IN THE HOSPITAL. SHE IS IN HILLSBOROUGH HOSPITAL.

BASED ON INCOME, DID NOT ALLOW US TO GET SUPPORT. OTHER THINGS NEED TO BE TAKEN INTO CONSIDERATION. I MAY HAVE TO STOP WORK IN ORDER TO DEAL WITH HIS DISABILITY, BECAUSE WE DID NOT GET ANY SUPPORT. I AM A NURSE, AND IF I HAVE TO QUIT, THAT WILL IMPACT THE HEALTH CARE SYSTEM IN ANOTHER WAY. MY SON IS 15, AND HE WILL NOT BE CONSIDERED AN ADULT UNTIL HE IS 25. WHICH MEANS ONCE HE IS OUT OF HIGH SCHOOL, THERE WILL BE NO FUNDING TO HELP HIM. WE CANNOT GET RESPITE BECAUSE OF THE LACK OF QUALIFIED HELP, ALSO IT IS SO EXPENSIVE. THE PROGRAM NEEDS TO IMPROVE.

THE REVIEW PROCESS ITSELF WAS EXTREMELY INAPPROPRIATE AND INEFFECTIVE FOR CHILDREN. THE PROGRAM WAS SET UP FOR ADULTS WITH DISABILITIES, THAT IS WHAT WE UNDERSTOOD.

EVERYTHING IS GREAT.

UNDER FAMILY SUPPORT PROGRAM HIS NEEDS WERE BEING MET, UNDER DSP OUR NET INCOME DEEMED HIM INELIGIBLE AND WE LOST ALL THE SUPPORT HE NEEDED. FINANCIALLY IT WAS SIGNIFICANT FOR US. I QUESTION THE WHY OF IT BECAUSE WE ARE IN A POSITION OF HARDSHIP DUE TO OUR HAVING TO MEET ALL HIS DISABILITY NEEDS. HE IS STILL DISABLED AND WE RECEIVE NO SUPPORT WHATSOEVER.

THE PROGRAM WORKS FOR MY OTHER TWO DSP LADIES, BUT IT DOES NOT WORK FOR []. I AM NOT HAPPY WITH THAT. IT COULD BE MADE A LOT EASIER TO FILL HER NEEDS UNDER DSP RATHER THAN HAVE HER INSTITUTIONALIZED. THE DSP PROCESS OF PICKING AND CHOOSING, WHO GETS IN AND WHO DOES NOT. SHE DOES NOT HAVE SCHIZOPHRENIA, IQ TEST SHOWS SHE IS MENTALLY HANDICAPPED, SHE HAS WALKING PROBLEMS, AS WELL AS BEING MANIC DEPRESSIVE, SHE IS HIGH NEED. I FEEL SHE HAS BEEN UNFAIRLY ASSESSED. SHE WAS TURNED DOWN FOR DSP SUPPORT BECAUSE SHE HAD SCHIZOPHRENIA.

THERE WAS NOTHING EXPLAINED 100% TO US, IT WAS ALL BASED ON INCOME, AS FAR AS THEY WERE CONCERNED WE SHOULD NOT HAVE EVEN BEEN APPLYING. WE NEED FINANCIAL HELP FOR PROGRAMS, THEY DO NOT UNDERSTAND THE ILLNESS, THE NEEDS, AND THE FINANCIAL BURDEN PLACED ON PARENTS WITH DISABLED FAMILY MEMBERS. THEY DID NOT UNDERSTAND ANYTHING. WE ARE JUST FRUSTRATED AND FED UP.

MY HUSBAND HAS [] AND I HAVE [] AND I HAVE JUST HAD BRAIN SURGERY. NEITHER OF US CAN WORK BECAUSE OF OUR DISABILITIES BUT THEY JUST TOLD US TO STAY ON WELFARE. THEY DID NOT TELL US WHERE ELSE WE COULD GO FOR HELP TO TRY TO GET HELP WITH OUR DISABILITIES. I DO NOT KNOW WHERE TO GO FOR HELP. I DO NOT KNOW IF I QUALIFY FOR CPP. EVERYTHING IS SO CONFUSING.

I NEEDED HELP WITH TRANSPORTATION, MY SIGHT IS BAD, AND I COULD NOT GET HELP. I THOUGHT THAT IS WHAT DSP WAS THERE FOR. I SEEM TO MANAGE ONLY BECAUSE I AM CAREFUL. I GET A NEIGHBOUR TO TAKE ME TO DOCTOR APPOINTMENTS, BUT I HAVE TO PAY HIM. DIFFERENT NEIGHBOURS HELP ME, BUT THEY ARE ALL BUSY, AND I AM DEPENDANT ON THEM, BUT WHY NOT DSP?

THE QUALITY OF THIS SURVEY IS ONLY FAIR I THINK.

Appendix F:

QUESTION: IS THERE ANYTHING ABOUT THE DISABILITY SUPPORT PROGRAM AND ITS SUPPORTS AND SERVICES THAT YOU WOULD LIKE TO COMMENT ON?

Very disappointed. Provincial government should pay something to disabled. I was told there was nothing so I didn't do the paperwork.

The program discriminates on account of age. The age of adulthood is 18, not 25 like the SP deems my son. The benefits shouldn't stop at 65; that is also discriminatory. They should take into account your present income, not last year's. This year, my income is only half of what it was last year, but they would never take that into account. The income screening process is unfair to mixed families.

This is the worst program in the world. They're not helping anybody. You must have to have the right name or something to get help. I know people getting help they don't deserve. It's badly set up.

People develop tunnel vision, they fail to see there are exceptions to every rule. I am very pleased with the workers, but the program itself is not sufficient for all families. It is amazing how little some people know about the program.

Compared to the old system there was consideration to family situations, but in this program there is just means testing. We have three disabled people in the house, but we didn't qualify for anything. I make good money, but I have three disabled people in my family! The case worker seems helpless to do anything to help.

The program is too limited and not flexible. Resources that are needed are not there. Speech therapy, child psychologists, physio, respite, tutoring, books and materials and computer software, occupational therapists for intensive work.

Special workers to place hard to place individuals. What can be done for highly functional disabled people...they fall through the cracks.

Program does not take into account differing needs of people with same diagnosis. It treats everyone alike and is inflexible instead of person-centred. The caps are ridiculous for a life-long disability and are also contrary to the stated philosophy of the program. Government does not put enough money into the program to give effect to stated aims. There's a big difference between stated philosophy of the program and the actual roll-out and implementation. There needs to be a more collaborative approach and more input from organizations in the disability community. The appeal process is deeply flawed with all DSP on the board, no citizen input and no one with an extensive background in disabilities.

Transportation...need to have that if we plan on working somewhere.

Advocates are needed to make the DSP listen and understand that these people have important needs and they're not being met. The DSP knows the program is no good but they don't listen to us. Instead they spend all this money on the survey to tell them the same thing we've been telling them all along! That's the beauty of government.

Heard about the DSP through word-of-mouth. They should advertise it more. Many people don't know it's there and what's available. Need a club for the disabled.

Found it straightforward. No more extra funds for just one week at camp.

My opinion is you shouldn't work, just sit down and they will help you. but if you work and try to keep a roof over your head and you get sick and spend all your money on medicine, they won't help you. Where is the sense in that?

Everything is based on income. Lazy poor get it all if disabled. Millionaires get it all but the working poor get nothing. We get fed up...we have an 18 year old disabled child and never got a thing. No compassion whatsoever!

We've been driven to distraction. It's a human rights issue and a complaint is filed. The DSP is a sham...it's unjust, it's a crime and outrageous. No matter how we fight it nothing changes. Government says 80% are happy with the DSP but 80% are unhappy. We're under house arrest.

I was just checking all resources to see where I could find assistance for a \$5,000 hearing aid recommended by the audiologist.

First time I dealt with the DSP and things went just fine.

Doctors recommend that children diagnosed with autism are helped right away...early intervention. We are on a waitlist for eight to nine months for a highly recommended program with no help from the DSP in the meantime. When the DSP does start, we'll have to pay a percent a month that is a fairly big chunk for a moderate income. In our area, there are no speech pathologists qualified to work with autistic children. If we could go outside of our area we could find someone who was qualified. We tried to receive other services such as speech and language, but DSP won't help us until the program that we are waiting for starts.

The program didn't serve much good at all. The Council for the Disabled gave all direction and moral support. The provincial government is three-quarters of the problem. It is directly responsible for legislation to deny benefits and cause poverty. They create more problems than they solve. They create work for government workers and everyone else suffers. Nothing short of suicides would satisfy the []...I want you to write that down! Most people with long-term disabilities are treated the same way...you have to have money to get help. The government system has no morals.

There is not much information available on the program. It seems difficult to find out what is covered and what is not.

Sometimes programs can hurt a person. The DSP was no good for me. It should uplift disabled people, not make them feel bad about themselves.

They didn't understand my problem and turned me down based on one phone call and they didn't look any further than that.

It was a time consuming interview and application process.